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03/25/19

Examining multilevel socioenvironmental factors associated with pursuit of kidney transplant  
among predominantly African American end stage renal disease patients undergoing dialysis

By

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Doctor of Philosophy

Behavioral Sciences and Health Education

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## Abstract

Examining multilevel socioenvironmental factors associated with pursuit of kidney transplant among predominantly African American end stage renal disease patients undergoing dialysis

By Shauna St. Clair Flemming

Kidney transplant is the recommended treatment for many people with end stage renal disease (ESRD). Kidney transplant recipients experience increased life expectancy, reduced hospitalization, and improved quality of life, compared to those who remain on dialysis. Still, low kidney transplantation rates are observed among ESRD patients in the U.S. African American (AA) patients are disproportionately impacted as they are 3 times more likely to advance to ESRD than white patients, but have 30% lower transplantation rates (United States Renal Data System, 2018). Racial disparities in transplantation may be explained in part by socioeconomic status (SES) inequalities. This dissertation conducted two studies to elucidate multi-level social and environmental factors associated with kidney transplant pursuit among predominantly AA ESRD patients receiving dialysis care from Atlanta, Emory-operated dialysis clinics, in order to promote equitable access to kidney transplant.

Our quantitative study examined associations between neighborhood-level SES characteristics of dialysis patients' (n=1118) physical, social, and service environments and kidney transplant wait-listing, using sequential cox proportional regression modeling. Secondary patient data was obtained from dialysis clinic electronic medical records and the United States Renal Data System. Patients' home neighborhood characteristics were collected using census-tract data from the 2011-2016 American Community Survey. In our qualitative study, we completed semi-structured interviews with AA hemodialysis patients (n=22) to assess how dialysis patients' social network functions (i.e. social influence, social undermining, social companionship, and social support) and experiences with SES declines while on dialysis influence kidney transplant pursuit.

Quantitative results showed increased exposure to SES disadvantages within patients' physical and social environments were associated with reduced waitlisting rates. Qualitative interview findings revealed that local family and successful transplant recipients provided important social influence, encouraging transplant. Family and other dialysis patients were resources for companionship and emotional social support but often limited in providing financial or informational social support for transplant pursuit. Most patients (59%) experienced declines in SES while on dialysis, which impeded transplant pursuit. Future efforts to promote equitable access to transplant should consider strategies that address neighborhood disadvantages, diversify social networks and strengthen SES for AA dialysis patients.

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## Chapter One - Introduction

### I. Background

#### A. The burden of end stage renal disease in the United States

End stage renal disease (ESRD) is a prevalent, serious, and costly condition within the United States, characterized by complete, permanent kidney failure. This condition is the fifth and final stage of chronic kidney disease, which more broadly describes the decline in kidney function over time (Table 1.1) (United States Renal Data System, 2018). Individuals with ESRD may experience excess fluid retention, waste build up, elevated blood pressure, and insufficient production of red blood cells (National Institute of Diabetes and Digestive and Kidney Diseases, 2013).

<b>Table 1.1: Stages of Chronic Kidney Disease</b>		
<b>Stage</b>	<b>Description</b>	<b>eGFR (ml/min per 1.73 m<sup>2</sup>)</b>
<b>1</b>	Kidney damage with normal kidney function	≤90
<b>2</b>	Mild reduction in kidney function	60-89
<b>3</b>	Moderate reduction in kidney function	30-59
<b>4</b>	Severe reduction in kidney function	15-29
<b>5</b>	Kidney failure	<15
* Stage descriptions reference the National Kidney Foundation's K/DOQI Clinical Practice Guidelines for chronic kidney disease (Hogg, Furth, & Lemley, 2003)		

More than 126,000 incident cases of ESRD were reported in 2016, contributing to a total prevalence of 726,331 (United States Renal Data System, 2018). It is additionally estimated that ten percent of the adult population, or 31 million people, have early stages of chronic kidney disease. However, most of these cases are undiagnosed, suggesting that the majority of people with kidney disease are not receiving appropriate medical care for their disease and are at higher risk for progressing to ESRD (United States Renal Data System, 2018).

Serious health conditions may result from ESRD. On average, people with renal failure experience elevated risk for high blood pressure, pulmonary edema, cardiovascular disease, central nervous system damage, and weakened immune systems compared to people with normal functioning kidneys. Additionally, ESRD patients experience reduced quality of life and lower life expectancy (Center for Disease Control, 2014; United States Renal Data System, 2018).

End stage renal disease also poses substantial economic burden. Patients with ESRD require costly medical procedures to replace the kidney's function with either ongoing dialysis treatment, or a kidney transplant. Approximately \$35.4 billion is spent annually on Medicare fee-for-service payments for ESRD patients, accounting for 7.1% of all paid Medicare claims. The majority of this healthcare spending is on the 468,000 Americans on dialysis (United States Renal Data System, 2018). Medical spending only accounts for a portion of costs associated with ESRD. Various non-medical costs (e.g. childcare and transportation expenses) are also incurred by ESRD patients, care-givers, and social programs (United Network for Organ Sharing, 2011).

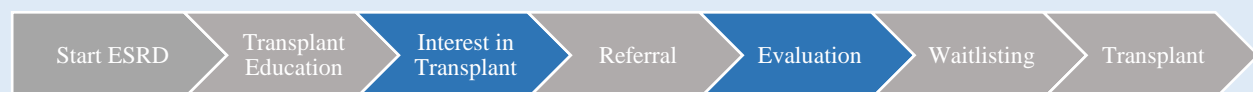
#### B. Treatment options for patients with ESRD

Dialysis and kidney transplant are the recommended renal therapy options available to ESRD patients. Dialysis refers to the clinical process of mechanically filtering the blood using a special machine in the absence of a viable kidney. There are two types of dialysis: 1) hemodialysis and 2) peritoneal dialysis. Hemodialysis treatments involve blood being filtered through machines operating outside of the body and are most commonly given within dialysis clinics during three to five-hour sessions, three times a week. Some patients with eligible health status and suitable housing conditions choose instead to receive, shorter, but more frequent hemodialysis treatments in their homes. Approximately 90% of dialysis patients receive hemodialysis treatment in dialysis clinics (United States Renal Data System, 2018). A second

type of dialysis is peritoneal dialysis. Peritoneal dialysis uses the belly lining to filter blood inside the body and is most commonly administered at home (National Institute of Diabetes and Digestive and Kidney Diseases, 2013). Only about 10% of prevalent ESRD patients receive peritoneal dialysis.

Kidney transplant surgery is an alternative to dialysis treatment. Kidney transplant surgery replaces the poorly functioning kidney with a living or deceased donor organ and is the established recommended treatment for many ESRD patients (United States Renal Data System, 2018). Kidney transplants are most commonly received by ESRD patients who have already initiated dialysis, although pre-emptive surgery prior to the initiation of dialysis is given to a small percentage (2.8%) of patients with kidney disease (United States Renal Data System, 2018). Receiving a kidney transplant requires ESRD patients to successfully complete several steps in a pathway to transplantation. The standard pathway from the onset of ESRD to successful deceased kidney transplantation involves patients receiving adequate education about kidney transplantation, expressing interest in receiving a transplant, being referred to a transplant center by a healthcare professional within their dialysis clinic, successfully completing an extensive evaluation process at a transplant center, and being added to a national waitlist until a kidney is allocated for transplant (Figure 1.1) (Patzner, Plantinga, Krisher, & Pastan, 2014). The pathway to successful living donor kidney transplantation is the same except that the waitlisting step is eliminated.

Figure 1.1: Steps to Transplant (Adapted from Patzner et al., 2014, p.1563)



*Note: Boxes highlighted in blue indicate steps in the pathway that require patient actions*

Numerous supports and resources are required for ESRD patients to progress across the transplant pathway and live with a kidney transplant. Medical and non-medical costs can be substantial. Anticipated medical expenses include payments for insurance deductibles and co-payments, pre-transplant evaluation and testing, surgery, recovery of the organ from the donor, follow-up care and testing, additional hospital stays for complications, healthcare provider fees, and rehabilitation care. Additionally, after receiving a kidney transplant, patients are required to take immunosuppressive drugs for the rest of their lives, which can easily exceed \$2,500 per month (Bently, 2014; United Network for Organ Sharing, 2011).

**Table 1.2: Average 2014 US Billed Medical Charges per Kidney Transplant (Bently, 2014)**

<b>30 days pre-transplant</b>	Procurement	Hospital Transplant Admission	Physician During Transplant	180 Days Post-Transplant Discharge	Outpatient Immuno-suppressants and Other RX	Total
<b>\$23,200</b>	\$84,400	\$119,600	\$20,500	\$66,800	\$19,800	\$334,300

In 2014 alone, \$334,400 in medical charges were billed per kidney transplant in the U.S. (Table 1.2) (Bently, 2014). Medicare, a federally managed public health insurance program established for the elderly but expanded in 1972 to provide coverage for all ESRD patients, covers the vast majority of these costs (Center for Medicare and Medicaid Services, 2014). However, transplant recipients are still responsible for paying 20% of Medicare-approved costs for doctor services in addition to various portions of transplant clinic charges (United Network for Organ Sharing, 2011). These charges can be considerably expensive. Additionally, ESRD patients younger than 65 become ineligible for Medicare 36 months after receiving a kidney transplant, despite their ongoing need to take costly immunosuppressant drugs to prevent their bodies' rejection of the donor kidney (Center for Medicare and Medicaid Services, 2014). Medical expenses not covered by Medicare are commonly covered by Medicaid (a public

insurance option for the extremely poor), by private insurance, or from out-of-pocket spending. Costs may be especially challenging for individuals who cannot afford private health insurance but have incomes too high to qualify for Medicaid (United Network for Organ Sharing, 2011).

There are also numerous non-medical costs associated with transplant including transportation to transplant center appointments, childcare, lost wages if employers do not pay for time patients or family members spend away from work, and lodging if the transplant center is not close to the patient's home (United Network for Organ Sharing, 2011). Non-financial resources are also needed to assist patients in pursuing a kidney transplant. Such assets may include a support system to provide care before and after transplant surgery, significant others who give emotional support, and reliable loved ones who assist with transportation.

Prior to being waitlisted for transplant, dialysis clinic and transplant center providers require patients to verify that they have enough resources to manage transplant-related costs and post-transplant immunosuppressant medications. Patients must also verify their access to adequate social support to navigate the transplantation process (Emory Healthcare Kidney Transplant Program, 2016). Individuals who cannot provide evidence of these resources generally do not get transplanted.

### C. Kidney transplantation rates remain low and unevenly distributed across populations

Transplantation is the medically recommended treatment for most ESRD patients. Patients receiving transplants, rather than continued dialysis therapy, experience improved quality of life (Chang, Winsett, Osama Gaber, & Hathaway, 2004; Joseph, Baines, Morris, & Jindal, 2003; Keown, 2001), greater participation in life activities (Purnell et al., 2013), lower rates of hospitalization and incurred hospital expenses (Patzner & Pastan, 2014; Patzner et al., 2014; Southeastern Kidney Council, 2014; Tonelli et al., 2011), and lower mortality risk (Meier



et al., 2001). The benefits of receiving a transplant, compared to remaining on dialysis, persist across all studied ethnic groups (Higgins & Fishman, 2006; Wolfe et al., 1999).

Transplantation remains the ideal treatment option, over dialysis, for patients across racial and SES categories despite evidence of socioeconomic inequities in U.S. transplant outcomes. For example, the long term relative risk of death attributed to transplantation is lower for white Americans than African Americans (AA) (Wolfe et al., 1999). Additionally, adjusted 3-year graft survival is lower for AAs than non-Hispanic whites (73.9% versus 82.6%). Still, across ethnic groups, patients who receive kidney transplants have reduced long-term risk of death compared to patients who remain on dialysis (Higgins & Fishman, 2006; Wolfe et al., 1999).

Despite its benefits, kidney transplantation rates remain lower than expected in the U.S. In 2012, only 3.7 percent of dialysis patients received transplants, with most instead remaining on dialysis, a sub-optimal treatment (United States Renal Data System, 2018). Low overall transplantation rates are largely due to insufficient supplies of donor organs, a barrier shown to differentially impact patients' access to transplantation across racial and socioeconomic lines (Ozminkowski, White, Hassol, & Murphy, 1998; United States Renal Data System, 2018).

Low kidney transplantation rates are disproportionately observed among AA and low income ESRD patient populations. African Americans are 3 times more likely to advance to ESRD than whites, but have 30% lower kidney transplant rates (United States Renal Data System, 2018). Similarly, individuals with lower SES are at greater risk for developing ESRD (Ward, 2008), but are less likely to undergo kidney transplant surgery (Ozminkowski et al., 1998).

Reducing racial and socioeconomic disparities in access to kidney transplantation is an important public health objective because ESRD is a prevalent, serious, costly problem that disproportionately burdens marginalized populations. Low transplantation rates may contribute to poorer health and quality of life and decreased life expectancy. Improving health outcomes for ESRD patients will require greater public health efforts to promote equitable access to kidney transplant. More research is needed that examines and intervenes on multilevel socio-environmental determinants of disparities in kidney transplantation. This dissertation seeks to examine multilevel social and environmental factors associated with transplant pursuit among predominantly AA ESRD patients undergoing dialysis.

## II. Literature Review

### A. Racial inequities in African American ESRD patients' pathway to kidney transplant.

The current literature suggests that AAs experience well documented inequities at every step in the pathway to kidney transplant, shown in Figure 1.1. African Americans are overrepresented within the ESRD patient population, with disease prevalence 3.7 times higher than white Americans (United States Renal Data System, 2018), but are less likely than white Americans to report having received information about transplantation or knowing about transplant while on dialysis (Kucirka, Grams, Balhara, Jaar, & Segev, 2012). African American patients are also more likely to report being unwilling to undergo transplant surgery and less likely to receive a referral for transplant from dialysis clinic healthcare providers (Ayanian, Cleary, Weissman, & Epstein, 1999; Higgins & Fishman, 2006). African Americans who do receive referrals to transplant centers are less likely to begin the transplant evaluation process than referred whites (Patzner, Perryman, Schragar, et al., 2012). And, as few as 49% of referred AAs complete the transplant evaluation process (Weng, Joffe, Feldman, & Mange, 2005).

African Americans with suitable evaluation results are granted placement on the transplant waitlist, but are more likely to remain on the transplant waitlist longer than white patients (Patzer, Perryman, Schrager, et al., 2012). Barriers to transplantation persist across the transplant pathway for AAs independent of disease complications, despite AA patients being younger, on average, than white dialysis patients. Younger age is a well-established transplantation advantage (Patzer, Perryman, Schrager, et al., 2012; United States Renal Data System, 2018). African American dialysis patients have transplantation rates 40% lower than white Americans in the U.S. (United States Renal Data System, 2018).

#### B. Multilevel socioeconomic disadvantages associated with African American ESRD patients' reduced access to transplantation rates

Multilevel social and economic disadvantages inequitably experienced by AAs may partially explain disparities in AA ESRD patients' progression to renal failure across the life course and success navigating the transplant pathway, compared to white patients (Patzer & McClellan, 2012; United States Renal Data System, 2018). This section presents study findings describing macro, mezzo, micro and individual-level socioeconomic factors that are associated with reduced kidney transplant rates and disproportionately experienced by AAs.

##### Macro

At the macro-level, national kidney allocation policies and socioeconomic disadvantage are strongly linked to racial disparities in access to transplant. National kidney allocation policies are guided by the challenge of organ scarcity, as the demand for kidney transplants far exceeds the supply of donor organs. In 2016, the active transplant waiting list was nearly three times greater than the quantity of available donor kidneys (United States Renal Data System, 2018). Given their limited supply, donor organs are not available to all patients who need them. Instead

allocation algorithms are used to determine patients' eligibility for transplant based on their ability to maximize the longevity of that organ. These policies emphasize organ utility over the equitable distribution of organs (Courtney & Maxwell, 2009).

Kidney allocation policies have contributed to racial disparities in access to transplant by allocating deceased donor organs to waitlisted AA patients at lower rates than white patients (United States Renal Data System, 2018). In 2014, a revised Kidney Allocation System, designed in part to reduce these inequities, implemented significant changes to allocation algorithms (Organ Procurement and Transplantation Network, 2014). In the new system, longer time on dialysis confers an advantage in matching with a donor organ. This policy change was intended to promote more equitable allocation outcomes for AAs patients who, compared to white patients, spend more time on dialysis before being evaluated for transplant (Organ Procurement and Transplantation Network, 2014; United States Renal Data System, 2018). Early evaluation of the revised Kidney Allocation System has been linked to reduced disparities between AA and white patients' kidney transplant rates (Massie et al., 2016; Melanson et al., 2017).

Macro-level socioeconomic disadvantage may also help to explain AAs' reduced access to kidney transplant because AAs dialysis patients are over-represented among lower SES groups (Higgins & Fishman, 2006; Navaneethan & Singh, 2006). Compared to whites patients, AA dialysis patients have lower incomes (Ozminkowski et al., 1998), more uninsured or publicly insured (Isaacs et al., 2000), possess less education (Epstein et al., 2000), and are less employed (Tzvetanov et al., 2014). For example, even among privately insured ESRD patient groups (an indication of higher SES), AA patients are half as likely to be employed (30.4% vs. 14.0%) (Tzvetanov et al., 2014).

Belonging to lower SES groups, indicated by lower levels of income, health insurance, education, and employment, is associated with poorer outcomes for ESRD patients (Keith, Ashby, Port, & Leichtman, 2008; Kurella-Tamura, Goldstein, Hall, Mitani, & Winkelmayr, 2014; Ozminkowski et al., 1998; Petersen et al., 2008). Ozminkowski et al. (Ozminkowski et al., 1998) found that low-income patients were half as likely to obtain a kidney transplant, compared to middle-income patients. High-income patients were 1.5 times more likely to be waitlisted and 2.6 times more likely to receive a transplant, compared to middle-income patients. Brown et. al. similarly found ESRD patients with higher incomes have greater odds of initiating the evaluation process at a transplant center (Browne, 2011)

Regarding insurance status, Keith et al. (2008) found that patients with Medicare as their primary health insurance spent more time on dialysis before being waitlisted, compared to those with private insurance. Similarly, Kurella et al. (2014) observed that patients who had Medicaid or no insurance were less likely to be waitlisted or to receive a transplant within one year of beginning dialysis compared to individuals with private insurance.

Research examining links between educational attainment and ESRD outcomes demonstrated that patients with less education also remained on the transplant waitlist longer than patients with higher levels of education (Keith et al., 2008). Studies exploring employment as a social determinant have found that employment status at the time of transplant has been strongly linked to patient and kidney graft survival rates (Petersen et al., 2008). Patients who are unemployed at the time of transplant are also less likely to secure jobs after transplant surgery (Tzvetanov et al., 2014), a characteristic that has been linked to poorer outcomes post-surgery (Rongey et al., 2005).

In addition to AAs being at greater risk for having lower SES, research suggests that the negative effects of low SES on transplant outcomes may be more strongly experienced among AA populations. Patzer et al. found that poor AA patients were 67% less likely to be placed on the donor waiting list than poor white patients (Patzer et al., 2009). Furthermore, minority patients with high educational attainment and private primary insurance waited longer to be waitlisted for transplant than similarly educated and insured white patients (Keith et al., 2008). Demonstrated economic disadvantage experienced by AAs in the U.S. may help explain racial and economic disparities in access to transplant.

### Mezzo

Mezzo-level socioenvironmental factors linked to racial disparities in transplant include neighborhood socioeconomic disadvantage. Indicators of neighborhood socioeconomic disadvantages have been linked to reduced access to kidney transplantation. For example, a study examining associations between spatial topography of poverty and kidney transplant rates within the continental U.S. identified a gradient relationship whereby lower county-level household income was associated with decreased kidney transplantation rates (Mohan et al., 2014). And, findings from a prospective cohort study of 3165 patients who developed ESRD similarly observed decreased neighborhood income to be associated with higher likelihood of mortality and lower likelihood of being added to the kidney transplant waitlist (Garg, Diener-West, & Powe, 2001).

Associations between neighborhood poverty and reduced access to transplantation may be especially troubling for AA populations, given that one in four poor AAs in the U.S. reside in high poverty census tracts. On average, an AA poor person is three times more likely to live in a poor neighborhood than a white American poor person (Jargowsky, 2015). In addition to having

greater exposure to poor neighborhood environments, AAs may also be disproportionately impacted by poor outcomes associated with community disadvantage. Johns et al. (2014) found that among 11,027 young adult ESRD patients living in low SES neighborhoods, AAs had higher all-cause mortality rates compared to white Americans, even after accounting for baseline demographics, clinical characteristics, rurality, and access to care factors. Similarly, Volkova et al. (2008), found that the elevated risk of ESRD incidence for AAs compared to whites increased with neighborhood poverty. A separate study found that as neighborhood poverty increased, gaps between AA and white American patients' waitlisting widened, with AAs residing in the poorest neighborhoods being 57% less likely to be waitlisted than white Americans living in the poorest neighborhoods (Patzner et al., 2009). These findings suggest that neighborhood socioeconomic disadvantages may have deeper adverse effects on AA ESRD patients' access to transplant than similar white American patient populations.

### Micro

Micro-level socioenvironmental factors associated with reduced access to kidney transplant experienced by AA ESRD patient populations include patients' social networks. Social networks describe the collections of overlapping linkages between individuals and others (Heaney & Israel, 2008). Individuals' social networks can vary structurally by their size (i.e. the number of members), by the density of connections, and by the types of interactions that occur between network members (Arthur, 2002). Social networks may also vary in how they function (Arthur, 2002; Israel, 1982). Key functions of social networks associated with individual health behaviors include social influence, social undermining, companionship and social support (House, 1981). Social influence refers to ways that the actions of others affect individuals' beliefs and behaviors. Social undermining describes individuals' health behavior goals being

impeded by others' actions or expressed criticisms (Heaney & Israel, 2008; House, 1981).

Companionship refers to the time spent with other individuals within the network. Social support is the most commonly examined function of social networks and focuses on the various forms of help or assistance provided between network members and is categorized into four types: emotional, instrumental, informational, and appraisal support (Table 1.3) (Heaney & Israel, 2008; House, 1981).

<b>Emotional Support</b>	Expressions of empathy, love, trust, caring
<b>Instrumental Support</b>	Tangible aid and services
<b>Informational Support</b>	Advice, suggestions, and information
<b>Appraisal Support</b>	Information that is useful for self-evaluation

Having a supportive social network is essential to ESRD patients' ability to successfully navigate the pathway to transplant and is linked to improved access to transplant in several ways (Browne, 2011; Clark, Hicks, Keogh, Epstein, & Ayanian, 2008; Emory Healthcare Kidney Transplant Program, 2016). For example, having a strong social support system is a common eligibility criterion for receiving a referral to a transplant center or being waitlisted. Having assistance from family and loved ones is deemed valuable in strengthening patients ability to comply with complicated, long-term post-transplant medical treatment plans (Organ Procurement and Transplantation Network, 2014).

Brown et al. (2011) additionally identified relationships between characteristics of ESRD patients' social networks and their likelihood of being seen for transplantation evaluation among a sample of 228 AA dialysis patients in Chicago, Illinois. The study found a greater total number



of social network members and informational social support from the dialysis team providing valuable knowledge about transplant to be positively associated with AA patients having accurate knowledge about kidney transplant (Browne, 2011). On average, patients who received more information about kidney transplant from their social networks, were also more likely to desire a transplant, to be seen at a transplant center, and to be waitlisted (Browne, 2011).

A separate study conducted by Clark et al. (2008) explored associations between social support networks and completion of a transplant evaluation. Researchers found that patients who received instrumental support with everyday tasks (e.g. cleaning and cooking) during the transplant process were more likely to complete a transplant center evaluation compared to those who did not receive instrumental support (25% compared to 46%) (Clark et al., 2008). Subgroup analysis adjusting for covariates demonstrated a strong relationship between instrumental social networks and evaluation completion for white men, white women, and Black women, but not Black men (Clark et al., 2008). Social networks that provide instrumental support may help ESRD patients perform behaviors that are important for transplant pursuit.

African American dialysis patients may have social networks that provide fewer supports for pursuing kidney transplant than white dialysis patients. Compared to whites dialysis patients, AAs have more homogenous social networks and have networks members who are less knowledgeable about transplant (B. A. Lee & Campbell, 1999; Malson, 1983). African American ESRD patients have less access to valuable information about transplant from their social network and are less likely to know people within their network who have successfully received a transplant (Browne, 2011; Campbell & Lee, 1992; B. A. Lee & Campbell, 1999; Malson, 1983).

Research examining social networks functions associated with kidney transplant often focus on the role of non-financial social support. More research is needed that explores social network roles besides social support, including social influence, social undermining, and social companionship(K. Ladin & Hanto, 2010). Additionally, studies that examine instrumental social support often emphasize non-financial support patients receive from network members (e.g. assistance with cooking). Better understanding the financial aspects of patients' social support may be important for addressing socioeconomic barriers to AA transplant pursuit.

### Individual

Individual-level socioenvironmental factors associated with reduced access to kidney transplant experienced by AA ESRD patient populations may include socioeconomic decline while on dialysis. Having and maintaining enough financial resources while on dialysis is important for patients to afford the costs associated with kidney transplant and for providers to perceive that dialysis patients are good candidates for transplant. However, undergoing dialysis may hinder socio-economic stability in several ways. Common physical side effects of dialysis, such as fatigue and nausea can make it difficult to participate in normal daily activities, including employment opportunities (Purnell et al., 2013). Patients undergoing dialysis can also experience weakened immune systems that can make them more prone to infections and other illnesses, leading to additional lost work (National Institute of Diabetes and Digestive and Kidney Diseases, 2013). And, in-center hemodialysis (the most common modality) requires that patients spend three to five hours receiving treatment three days a week, with very few clinics offering evening treatment hours (United States Renal Data System, 2018). This substantial time commitment can make it difficult for patients to maintain full-time employment.

Loss of employment or reduced work hours can have a significant impact on other indicators of patients' SES and impede successful transition across the transplant pathway. For example, dropping below full time status can influence patients' eligibility for private health insurance, which is most commonly employee-based in the U.S. (Janicki, 2013). Additionally, working less can cause reduced income and the loss of valuable resources such as reliable transportation. Experienced declines in SES may have lasting effects on patients by making it difficult to comply with routine dialysis treatments or evaluation procedures. And, individuals with lower SES may not be able to demonstrate to providers that they will be able to afford the financial costs associated with medical and non-medical treatments leading up to transplant or the costly immunosuppressant medication required post-transplant once Medicare insurance benefits have expired. Individuals who are unable to verify their ability to pay for these expenses may be deemed ineligible for transplant. It is also possible that lower SES ESRD patients concerned by high transplant costs, may assume they cannot afford it and choose not to pursue transplants (Ganji et al., 2014).

Socioeconomic decline while on dialysis may be especially impactful in shaping AA dialysis patients' access to transplant. Given their inequitable experiences with macro-level socioeconomic disadvantage, mezzo-level neighborhood socioeconomic disadvantage, and weaker micro-level social networks, compared to whites, AAs may be more vulnerable to socioeconomic decline while on dialysis. More research is needed to understand the complexities of changes in SES experienced by AA ESRD patients while on dialysis. Existing studies have focused overwhelmingly on loss of employment as an indicator of change in SES (Nakayama et al., 2015; Tzvetanov et al., 2014). For example, a 2015 study conducted in Japan, surveyed 179 hemodialysis and peritoneal dialysis patients to examine their ability to sustain their SES while

on dialysis, observing significant declines in employment and individual income while on dialysis (Nakayama et al., 2015). However, few studies have explored changes experienced in other key indicators of SES, such as income and insurance status or changes in types of employment (Rongey et al., 2005). Additionally, no studies to my knowledge have explored ways that AA patients' SES before initiating dialysis may facilitate or protect them from potential SES decline while on dialysis.

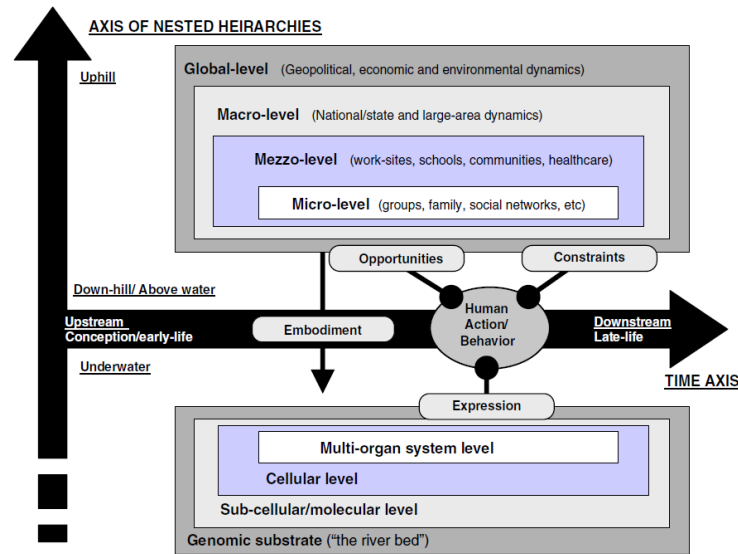
### C. Increasing African American ESRD patients' access to kidney transplant

Racial disparities in pursuit of kidney transplant experienced by AAs across the transplant pathway are well documented (United States Renal Data System, 2018). Evidence suggests that observed differences can be explained, in part, by socio-economic inequalities (Higgins & Fishman, 2006). However, much of this work has focused on individual-level determinants of ESRD patient outcomes rather than higher level factors that drive behavior often beyond individual control, with few exceptions (Patzner et al., 2009; Patzner et al., 2015; L. Plantinga et al., 2014). Developing interventions that promote greater equity in access to kidney transplant will require creative, innovative multilevel policy and environmental changes that increase access to kidney transplant for AA populations. This dissertation identifies AA ESRD patients receiving care in one of three Atlanta dialysis clinics as its priority population and relies on the perspectives of this population to elucidate understanding about the multilevel socioenvironmental factors associated with pursuit of kidney transplant with the intent of using these findings to inform the approach and content of future interventions that reduce disparities in access to transplant.

### III. Theoretical Approach

This dissertation contributes to the body of literature exploring multilevel socioenvironmental determinants of ESRD patients' access to kidney transplant using a theoretical approach that is guided by the Socioecological Framework presented by Glass and McAtee (2006) (Figure 1.2) and the Health Impact Pyramid introduced by Frieden (2010) (Figure 1.3). This study incorporates concepts from the three dimensional Social-Ecological Framework as a "root-metaphor" useful for contextualizing theories to examine factors linked to ESRD patients' pursuit of kidney transplant (Glass & McAtee, 2006). Glass and McAtee's (2006) socioecological model contains vertical and horizontal axes. The vertical axis describes nested socioecological levels of behavior determinants. Increased elevation on the vertical axis indicates higher social ecological planes, ascending from the individual-level to micro, mezzo and macro-levels, which are increasingly beyond individual control. Factors above the individual-level shape behavioral outcomes by producing opportunities and constraints for individual actions. Individual-level characteristics, such as race and income, are not explored as behavioral determinants to emphasize the impact of higher-level factors, such as racial discrimination and classism, as causes of behavior outcomes. This framework's approach considers ways that higher level determinants are "embodied," in individuals or influence modifiable individual characteristics, such as personal resources, to in-turn further influence health behavior.

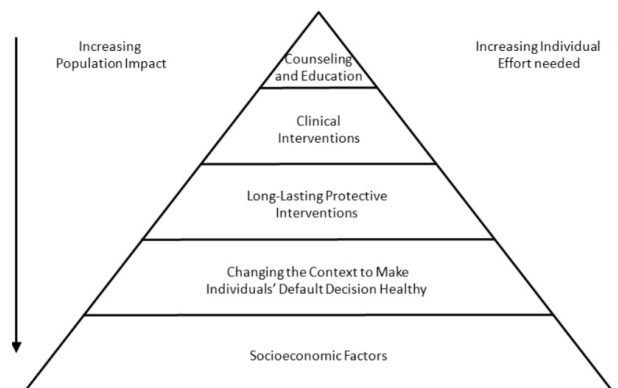
Figure 1.2: Social Ecological Model Presented by Glass and McAtee (2006)



This dissertation is also guided by Frieden’s Health Impact Pyramid (Figure 1.3), which encourages research focused on higher level (rather than individual level) socioeconomic determinants of population health. This emphasis reflects evidence that addressing higher level factors maximizes possible population impact while minimizing individual effort to achieve the desired health behaviors (Frieden, 2010).

An additional theoretical framework, MacArthur’s Conceptual Model of Pathways by which SES Influences Health (Figure 1.4), was adapted for this project to develop a theoretical model explaining multi-level socio environmental factors associated with racial and economic disparities in

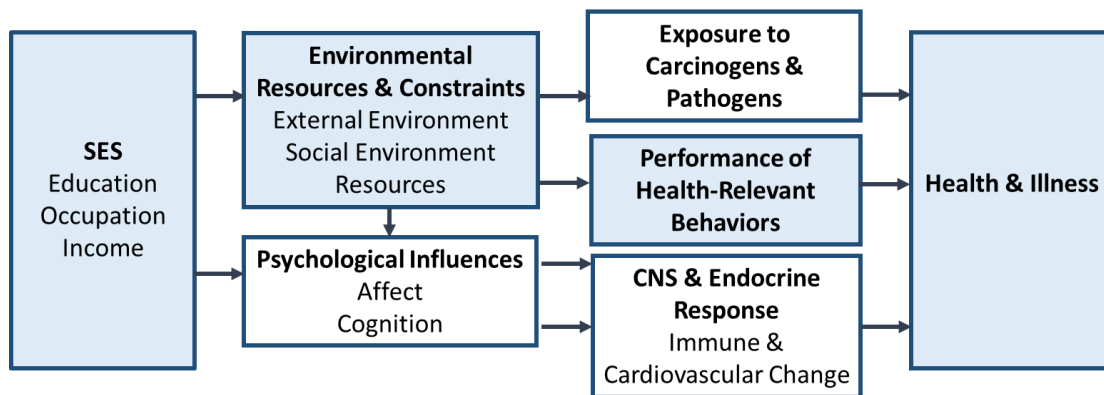
Figure 1.3: Health Impact Pyramid (Frieden, 2010)



pursuit of kidney transplant among predominantly AA ESRD patients undergoing dialysis. The sections below describe this dissertation's theoretical model and the application of key supplemental theories used to support three dissertation papers.

The conceptual model of the pathway by which SES influences health, shown in Figure 1.4, was described by Adler and Ostrove and developed by the MacArthur Network on SES and Health to help guide research on the ways in which SES is embodied to influence individual health (Adler & Ostrove, 1999). Within this model, indicators of community SES directly impact environmental resources and psychological influences, which subsequently impact environmental exposures to carcinogens and pathogens, performance of health-relevant behaviors, and the body's Central Nervous System and Endocrine stress responses. These environmental exposures, performed behaviors, and stress responses impact individuals' health and illness.

Figure 1.4: Model of the Pathways by which SES Influences Health (Adler & Ostrove, 1999)



(\*Blue highlighted boxes indicate constructs emphasized by this dissertation)

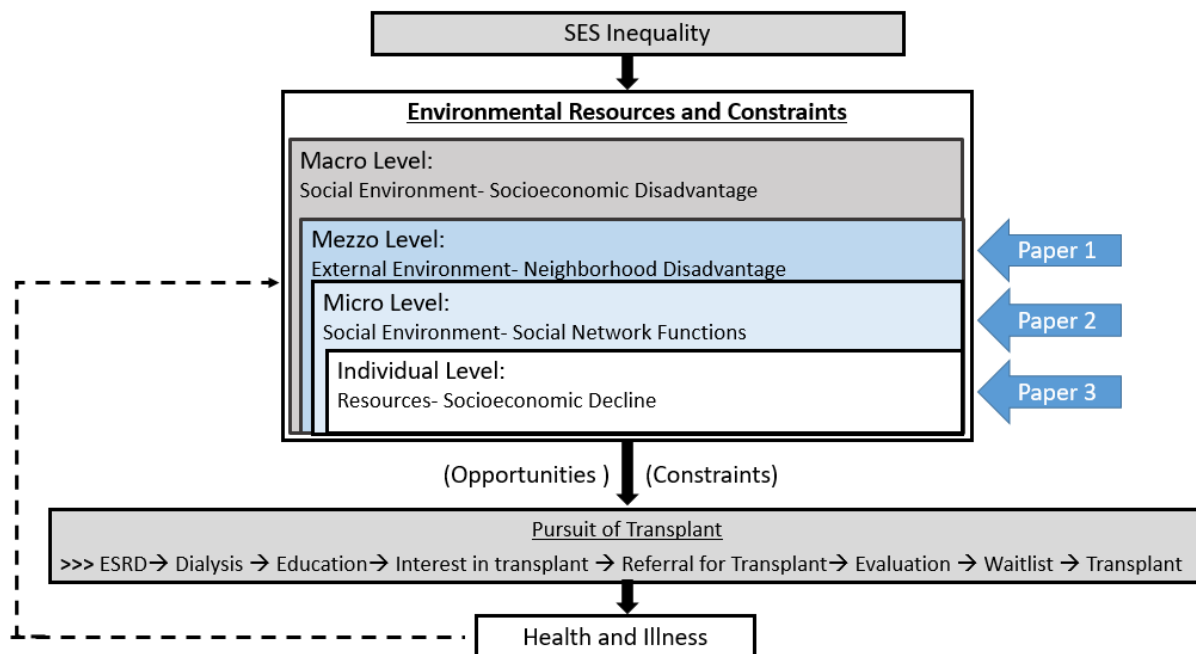
The MacArthur Network model incorporates a social causation pathway for exploring chronic disease outcomes for conditions such as ESRD, suggesting that SES is a determinant of Health and Illness rather than a result of Health and Illness. This causal direction is supported in

part by literature establishing the temporality of economic status preceding disease outcomes, including research demonstrating that childhood SES predicts adult health outcomes regardless of adult SES and studies showing that education acquired in childhood help explain health problems that begin many years later (Hertzman, 1999). The influence of SES on ESRD, in particular, has been further supported by observations of a gradient relationship across race and sex groups whereby higher SES predicts lower risk for the disease (Ward, 2008). While emphasizing the social causation pathway in their model, the authors also acknowledge that reciprocal relationships may emerge by which feedback loops exist between poor health and SES.

This dissertation adapts the MacArthur framework to provide a theoretical model describing the relationship between SES and pursuit of kidney transplant, shown in Figure 1.5. This model emphasizes the links between SES characteristics, environmental resources and constraints, and performance of health-relevant behaviors to Health and Illness (highlighted in blue in Figure 1.4). The remaining constructs- Psychological Influences, Exposures to carcinogens and pathogens, CNS and Endocrine Response are beyond the scope of this dissertation and will not be measured or analyzed in the current study.



Figure 1.5: Dissertation Theoretical Model Describing Multilevel Socioenvironmental Determinants of Kidney Transplant Pursuit



The remaining sections describe the theoretical constructs outlined in Figure 1.5 which are explored by this project.

### Pursuit of Transplant

The health behavior explored in the described theoretical model is ESRD patients' standard pursuit of a kidney transplant. This pursuit exists across a linear pathway shown in Figure 1.1. Ideally, ESRD patients that successfully transition from receiving dialysis therapy to obtaining a deceased donor kidney transplant will be educated about kidney transplant as an alternative to ongoing dialysis, express an interest in transplant, receive a dialysis clinic referral for evaluation at a transplant center, complete the transplant evaluation process, be added to the transplant waitlist and undergo kidney transplant surgery. Some steps in this pathway emphasize patient actions. For example, expressing interest in transplant and visiting the transplant center

for evaluation describe explicit actions patients take to pursue a kidney transplant. These patient-focused action steps are highlighted in blue in Figure 1.1. Other steps in the pathway to transplant require significant others to perform actions that indirectly influence patients' actions, but directly influence access to transplant. For example, neurologists are typically needed to refer ESRD patients for transplant and describe patient's access to transplant. Understanding patients' actions in pursuing transplant and the actions of significant others in shaping access to transplant are all important for understanding patients' success in progressing in the pathway of transplant pursuit. This dissertation emphasizes two points in the transplant pursuit pathway: 1) expressing interest in transplant, and 2) being waitlisted for kidney transplant.

### Health and Illness

Adler and Ostrove (1999) posit that behaviors performed by individuals can ultimately protect or promote Health and Illness. Within the context of ESRD, patients who do not receive a kidney transplant are more likely to experience risk for illness and longer life expectancy, compared to individuals who remain on dialysis (National Institute of Diabetes and Digestive and Kidney Diseases, 2013; United States Renal Data System, 2018). Distal health and illness outcomes were not assessed in this study as it is beyond the scope of the projects' timeline. However, it is included in the model to emphasize the significance of exploring pursuit of transplant to individual health outcomes.

### SES

Socioeconomic status is the fundamental determinant explored in this model, operationalized by considering income, education, and occupation as indicators of economic

status. Socioeconomic status influences population health by impacting the multilevel socioenvironmental resources to which population groups are exposed.

### Multilevel Socioenvironmental Resources

Alder and Ostrove (1999) describe Socio-environmental Resources to refer to the External Environments, Social Environments and Resources that vary among individuals in a society based on their SES. These constructs are explored in the described model by considering these three constructs operating across mezzo, micro, and individual social ecological levels, respectively. This project additionally inserts a macro-level socioenvironmental resource for exploration. This modification is a logical continuation of the original model, given the authors' advisement that future research give greater consideration to higher level social determinants (Adler & Ostrove, 1999).

### Macro-level Social Environment

Macro-level Social Environment is conceptualized in this project by considering the influence of socioeconomic inequality operating at national and state-levels. The importance of socioeconomic inequality is elaborated by the Theory of Fundamental Causes introduced by Link and Phelan (1996) to explain why links between SES levels and healthcare outcomes persist over time despite ongoing changes in risk factors and treatments associated with health outcomes. The theory posits that fundamental causes are resources such as knowledge, money, power, prestige, and social connections that effect individuals' ability to reduce their risks for diseases and prevent disease complications. Because populations adapt how they use these resources in given situations over time, the impact of these fundamental causes persist across numerous diseases or conditions of interest.

In the United States and within the context of ESRD, kidney allocation policies and socioeconomic inequalities are fundamental causes that grants groups with greater knowledge, money, power, prestige, and social connections greater opportunities to pursue kidney transplant. Link and Phelan (1996) maintain that effectively reducing disparities in healthcare access and related health outcomes will, first, require addressing higher level policies that establish and institutionalize social inequalities. This theoretical approach is further conveyed by the World Health Organization's (WHO) commission on social determinants of health (2008) by maintaining that successfully addressing health inequities will require that societies first address inequalities in the ways that these societies are organized by providing more equal distribution of power, money, and resources. The inclusion of more equitable kidney allocation algorithms in the 2014 revised KAS may provide an important example of macro-level redistribution of resources to eliminate social disparities in access to transplant (Melanson et al., 2017; Organ Procurement and Transplantation Network, 2014).

#### Mezzo-level External Environment

The mezzo-level external environment is explored in Chapter Two by examining neighborhood-level characteristics linked to pursuit of kidney transplant. Adler and Ostrove (1999) describe that neighborhood conditions can constrain or facilitate individual health. This relationship is further expanded by Kirby and Kaneda (2005) who suggest that neighborhood socioeconomic disadvantage facilitate or impede individual-level health and health behaviors by negatively influencing neighborhood-level physical, service, and social environments. Applying this model within the context of pursuit of ESRD, neighborhood physical environments reflect the availability or lack of community resources and can be seen in tangible community characteristics that directly threaten health or impede health behavior, such as overpopulated

housing projects. Services refer to accessible healthcare resources including dialysis and transplant clinics needed to facilitate access to healthcare. And, social environments reference spaces or opportunities for social interaction and support (Kirby & Kaneda, 2005). For example, accessible stable family units and engaging community organizations could be institutions that facilitate social support and information sharing. Kirby and Kaneda argue that neighborhood-level deprivation can act on these environmental characteristics to influence behavior and health independent of the individual-level characteristics of people living in these neighborhoods (2005). This suggests that poor health outcomes observed in lower SES neighborhoods cannot be simply explained by the aggregated socioeconomic statuses of the people who live there. Instead characteristics of disadvantaged neighborhoods themselves promote poorer health. Paper one from the described dissertation examines the ways in which characteristics of dialysis patients' neighborhood-level physical environment, service environment, and social environment influence pursuit of kidney transplant.

### Micro-Level Social Environment

The Micro-Level Social Environment is explored in Chapter Three by examining the relationship between social network functions and pursuit of transplant. This construct can be further elucidated by Social Networks literature. Social Networks describe the collections of overlapping connections between individuals and others (Heaney & Israel, 2008). Several seminal papers describing Social Networks and their associations with individual health behaviors were published in the 1980s, with significant contributions coming from Israel and House et al. (House, 1981; House, Landis, & Umberson, 1988; Israel, 1982). A central premise of these works is that social network relationships have important causal impacts on individuals' health (Heaney & Israel, 2008; House et al., 1988). Existing studies support links between social

networks and health outcomes across numerous health topics including cardiovascular disease (Berkman & Glass, 2000), all-cause mortality (LaVeist, Sellers, Brown, & Nickerson, 1997), and ESRD (Browne, 2011; Clark et al., 2008; L. C. Plantinga et al., 2010).

Social networks are generally studied in one of two ways. The first is by examining entire network systems and the connections between and among networks. This approach focuses on the structural characteristics describing linkages and the size and density of the overall network and the nature of social interactions (Arthur, 2002; Israel, 1982). Alternatively, researchers focus on the point of view of individuals and their interactions with members in their networks. This perspective emphasizes social networks' functional characteristics and describes the roles network members serve (Israel, 1982). Chapter Three applies the latter approach and focuses on the functions of ESRD patients' social networks. This project considers social network functions as factors that operate through social influence, social undermining, companionship and social support to impact individual health behaviors related to pursuit of kidney transplant (House, 1981).

### Individual-level Resources

Individual-level resources are explored in Chapter Four to examine the relationship between socioeconomic decline while on dialysis and pursuit of transplant. Adler and Ostrove (1999) suggest that individuals' access to resources can impact their ability to perform behaviors that promote or protect health and illness. Within the context of ESRD, empirical data demonstrate significant individual-level financial resources ESRD patients must possess to afford medical and non-medical expenses that accrue across the pathway to transplant in addition to costs associated with managing immunosuppressant drugs and other healthcare costs post-transplant (Table 1.2). Resources are also needed to manage non-medical costs, such as

transportation to and from the transplant center, child-care expenses, and lost wages from missed work for patients and their care-givers, which are often overlooked in studies examining costs associated with transplant.

There are several financial sources patients may use to manage costs encountered on the transplant pathway, including Medicare, Medicaid, private insurance, and personal income and savings. Alternatively, patients may have access to assets they can liquidate, financial support from loved ones or assistance from various transplant support programs (United Network for Organ Sharing, 2011) . However, apart from Medicare, individuals' SES may largely determine their access to these resources. For example, Medicaid is a financial resource for individuals living in severe poverty. However, there remain over 3 million adults in the U.S who do not qualify for Medicaid but are too poor to afford private insurance, AAs are over-represented within this population (Garfield & Damico, 2016). Similarly, lower SES individuals have less access to expendable income and are more likely to not have private insurance due to unemployment or underemployment (Janicki, 2013). Patients who do not have adequate financial resources may be overwhelmingly burdened by the cost of a kidney transplant or excluded from receiving a transplant.

Patients who experience SES declines while on dialysis may be especially vulnerable to having inadequate resources to pursue transplant (Nakayama et al., 2015). People who begin dialysis within lower SES may be overrepresented in this group.

Based on the model presented by Adler and Ostrove (1999) individual-level resources can facilitate or impede ESRD patients' pursuit of transplant. Relatedly, reduced access to transplant may occur in several ways. For example, patients may perceive they are unable to afford a kidney transplant (this belief could be accurate or misinformed) and thus decide not to

pursue a kidney transplant. Alternatively, individuals who are unable to verify their ability to manage transplant-related costs may be deemed ineligible for transplant by healthcare professionals based on transplant center criteria for wait-listing.

Chapter Four examines the relationship between ESRD patients' individual-level resources while on dialysis and pursuit of kidney transplant. This project gives attention to ways that being on dialysis and having lower SES prior to dialysis can further impede patients' ability to maintain financial resources that facilitate progression towards transplant. The theoretical approach applied in this study explores individual-level characteristics but consider that these constructs reflect the embodiment of higher-level macro-level socioeconomic inequalities, mezzo-level neighborhood disadvantage, and micro-level social network functions. Thus, addressing observed individual-level inequalities will require intervention at higher socioecological levels (Glass & McAtee, 2006).

#### IV. Significance and Aims of Research

This dissertation project seeks to address racial and socioeconomic disparities in access to kidney transplant by elucidating knowledge about multi-level social and environmental factors associated with transplant pursuit among predominantly AA ESRD patients undergoing dialysis. To achieve this goal, we carried out two distinct studies designed to (1) quantitatively measure associations between neighborhood-level socioeconomic characteristics of dialysis patients' physical, social, and service environments and kidney transplant wait-listing rates, using time-to-event cox regression modeling and to (2) qualitatively assess how functions of dialysis patients' social networks (i.e. social influence, social undermining, social companionship, and social support) and (3) experiences with socioeconomic declines while on dialysis influence patients' interest in and pursuit of kidney transplant.



This projects' multi-level approach is guided by evidence that racial and economic disparities observed in access to kidney transplant are not fully explained by patient-level determinants (Patzner et al., 2014; Volkova et al., 2008). At the mezzo level, external environments also play an important role in shaping individual health and illness (Adler & Ostrove, 1999). In particular, socioeconomic disadvantage encountered by patients may influence health behavior and health outcomes by predisposing individuals to physical, service, and social environments that enhance or reduce their ability to access healthcare (Kirby & Kaneda, 2005). Characteristics of dialysis patients' neighborhood environments and their associations with access to transplant are largely understudied. Studies that have examined these relationships support links between neighborhood poverty and poor ESRD health outcomes (Johns et al., 2014; Patzner et al., 2009). However, these projects have primarily examined the health impacts of living in areas with higher concentrations of low-income residents; rather than considering how specific features of poor neighborhood environments may influence health. This dissertation builds upon previous work by uniquely examining links between socioeconomic features seen in physical, social and service environments and access to transplant. This approach is useful as it may generate ideas for novel intervention strategies to improve transplant outcomes.

At the micro level, less supportive social networks are linked to reduced access to kidney transplant for AAs (Arthur, 2002; Browne, 2011). African American patients are more likely than whites to have dense, homogenous social networks with fewer connections to transplant-related knowledge which may contribute to racial inequities related to transplant (Browne, 2011; United States Renal Data System, 2018). Not enough is understood about AA dialysis patients' social networks and their relationships with kidney transplant. Existing studies have

overwhelmingly focused on social support while other social network functions are understudied (K. Ladin & Hanto, 2010) (Clark et al., 2008). This dissertation extends previous studies by examining ways AA social networks function to provide social influence, undermining and companionship in addition to social support.

At the individual-level, SES declines experienced while on dialysis may exacerbate financial challenges dialysis patients already face with managing transplant-related costs (United States Renal Data System, 2018). Previous studies support links between decreased SES and poorer access to transplant but primarily capture SES using quantitative employment and income indicators (Nakayama et al., 2015; Tzvetanov et al., 2014). Not enough is understood about how other SES characteristics or resources may impact patients' pursuit of kidney transplant. This study uses qualitative methods to explore AA ESRD patients experiences with declines in SES and reduced access to important transplant-related resources while on dialysis which may provide greater opportunities to explaining these relationships.

This dissertation's focus on determinants of pursuit of transplant across multiple social-ecological levels with an emphasis on identifying modifiable factors beyond patient control (Glass & McAtee, 2006). This approach is driven, in part, by evidence that addressing higher level factors maximizes possible population impact while minimizing individual effort to achieve health behavior change (Frieden, 2010). This dissertation's theoretical describes the relationship between multilevel socioenvironmental factors associated with pursuit of transplant and is adapted from Mac-Author's Conceptual Model of the Pathways by which SES influences Health (Figure 1.5). This project applies a concurrent triangulation methodological approach whereby qualitative key informant interviews and quantitative secondary data collection are conducted and analyzed within the same study period and prioritized equally in helping to explain different

aspects of the relationships examined (Creswell & Plano Clark, 2007). This dissertation considers each of these papers to be valuable in contributing to a fuller, contextualized understanding of the multi-level factors that help to explain barriers and facilitators in the pathway to kidney transplantation among predominantly AA ESRD patients, who are at greater risk for reduced access to transplant.

The specific aims of this dissertation project are as follows:

Aim 1. To identify socioeconomic characteristics of dialysis patients physical, social and service environments associated with waitlisting for kidney transplant.

Aim 2. To describe patients' social networks while on dialysis and how they shape pursuit of transplant

Aim 3. To describe patient experiences with declines in socioeconomic status while on dialysis and how they shape pursuit of kidney transplant.

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## Chapter Two - Neighborhood Socioeconomic Features and Waitlisting

A quantitative study examining associations between neighborhood socioeconomic disadvantage and access to kidney transplant among predominantly African American dialysis patients

### I. Introduction

End Stage Renal Disease is the final, progressive stage of chronic kidney disease. Individuals with ESRD experience irreversible kidney failure and must either undergo kidney transplant surgery or receive routine dialysis treatments to survive. Kidney transplant surgery is the recommended treatment for ESRD patients and is associated with improved patient survival and quality of life (Meier et al., 2001; Ozminkowski et al., 1998; United States Renal Data System, 2018). Yet, few ESRD patients in the U.S. receive kidney transplants (United States Renal Data System, 2018). In 2016, only 2.8 percent of incident ESRD patients received kidney transplants within the first year of diagnosis. Low rates of kidney transplant observed in the U.S. are primarily to due to scarce supplies of donor organs.

Kidney transplant rates vary across geographical regions in the U.S. with data suggesting that social and environmental factors may impact access to transplant (United States Renal Data System, 2018). On average, dialysis patients living in the Southeast are less likely to receive kidney transplants than dialysis patients living in other regions of the U.S. (Patzner & Pastan, 2014; United States Renal Data System, 2018). Studies have attributed low kidney rates observed in this region to patient-level poverty (Axelrod et al., 2010; McLeroy, Bibeau, Steckler, & Glanz, 1988; Ozminkowski et al., 1998; Patzner, Perryman, Schrage, et al., 2012). For example, lower socioeconomic status (SES) is associated with greater risk of developing ESRD (Ward, 2008), but reduced access to kidney transplant (Akistanbullu & Yilmaz Ulusoy, 2017). On average, ESRD patients who are unemployed, have public health insurance (such as

Medicare or Medicaid), or have lower educational attainment are less successful in obtaining a kidney transplant, compared to individuals with higher SES characteristics (Keith, Ashby, Port, & Leichtman, 2008; Kurella-Tamura, Goldstein, Hall, Mitani, & Winkelmayr, 2014; Ozminkowski et al., 1998; R. Patzer et al., 2009; Petersen et al., 2008).

Associations between individual SES and access to kidney transplant may partially reflect challenges patients face in managing essential medical costs associated with kidney transplant. In 2016, \$347,780 in medical charges were billed per kidney transplant in the U.S. (Table 1.2) (United States Renal Data System, 2018). Medicare, a federally managed public health insurance program established for the elderly but expanded in 1972 to provide coverage for all ESRD patients, covers the vast majority of these costs (Center for Medicare and Medicaid Services, 2014). However, transplant recipients are still responsible for paying 20% of Medicare-approved costs for doctor services in addition to various portions of transplant clinic charges (United Network for Organ Sharing, 2011). Medical expenses not covered by Medicare are commonly covered by Medicaid (a public insurance option for the extremely poor), by private insurance, or from out-of-pocket spending. Costs may be especially challenging for individuals who cannot afford private health insurance but have incomes too high to qualify for Medicaid (United Network for Organ Sharing, 2011). Challenges with affording transplant-related medical expenses may impede ESRD patients' success in completing the transplant evaluation process and being added to the transplant waiting list (Ganji et al., 2014). Still, variation in patients' SES do not fully explain poor kidney transplant rates (United States Renal Data System, 2018).

Adler and Ostrove (1999) posit that, in addition to individual-level characteristics, the external environments in which people live play a vital role in shaping their health behaviors,

wellness and disease outcomes. Kirby and Kaneda (2005) maintain that neighborhood socioeconomic disadvantage encountered by patients may influence health by predisposing individuals to physical, social and service environments that strain their ability to access healthcare. Within the context of ESRD, dialysis patients living in poorly resourced communities may encounter physical, social and service contexts that reduce access kidney transplant. Physical neighborhood features refer to tangible characteristics of the built environment. For example, high concentrations of vacant housing units are associated with increased crime and greater neighborhood disorder which may induce stress and impede the performance of healthy behaviors (Cui & Walsh, 2015; Han, 2014; Wang & Immergluck, 2018). High home vacancy rates are also associated with declines in home values, fewer employment opportunities, weaker social service infrastructures and reduced social capital (D. Cohen et al., 2003; Wang & Immergluck, 2018). Thus, ESRD patients living in communities with more empty homes may have less access to financial resources. Living in a physical environment with a high concentration of vacant homes may pose risks for poor health and chronic kidney disease and make it more challenging for ESRD patients to access kidney transplant (D. Cohen et al., 2003; Wang & Immergluck, 2018).

The social environment refers to the spaces or opportunities for social interaction and support (Kirby & Kaneda, 2005). Neighborhood family compositions are one aspect of social environment characteristics associated with socioeconomic resources. For example, on average, lower SES neighborhoods in the U.S. have higher rates of single parent families (United States Census Bureau/ American Fact Finder, 2016). High rates of single parent families are linked to weaker social cohesion, reduced social support and less information sharing related to kidney transplant (Volkova et al., 2008; Yen & Kaplan, 1999). Features of the neighborhood service

environment include resources that enable or impede residents' ability to access healthcare (Andersen, 1995; Kirby & Kaneda, 2005). Communities with more medically uninsured residents are associated with higher unemployment and reduced access to healthcare services (Garfield & Damico, 2016). High neighborhood uninsured rates may influence individual health behaviors by modifying social norms regarding healthcare utilization or disincentivizing healthcare providers from establishing services in these neighborhoods (Nikpay, Buchmueller, & Levy, 2016).

Socioeconomic disadvantage, visible in the neighborhood-level physical, social and service environment, may negatively impact community health outcomes, even after adjusting for individual-level characteristics of the people living in these neighborhoods (Adler & Ostrove, 1999; Kirby & Kaneda, 2005). This would suggest that poor health outcomes observed in lower SES neighborhoods are not simply explained by aggregated measures of patient-level SES. Instead the characteristics of disadvantaged neighborhoods themselves may promote poorer health by reducing access to resources that support healthy behaviors (Kirby & Kaneda, 2005).

Geographical variation in access to kidney transplant highlights the importance of understanding the socioeconomic characteristics of the neighborhoods in which dialysis patients live and the role these external environments may play in enabling or constraining ESRD patients' access to kidney transplant. Few studies have explored the relationship between neighborhood-level socioeconomic disadvantage and ESRD outcomes, with several key exceptions including research by Patzer and colleagues (Patzer et al., 2009; Patzer, Perryman, Schragar, et al., 2012) supporting links between neighborhood-level poverty and kidney transplant pursuit and the research of Johns et al., describing associations between neighborhood-level poverty and dialysis survival rates among young adult dialysis patients (Johns et al., 2014).



However, these studies use census tract-level poverty rates to describe neighborhood SES exposures, rather than examining other neighborhood socioeconomic characteristics. Poverty is one of many economic characteristics; but there may be others that more clearly explain barriers to transplant and that identify more readily available intervention opportunities. Plantinga and colleagues assessed several economic attributes of dialysis facility neighborhoods (e.g. community deprivation, cohesion, and housing), and found moderate associations between census-tract level exposures and kidney transplantation rates (L. Plantinga et al., 2014). However, this study examined characteristics of the neighborhoods in which patients' dialysis clinics were located, rather than the communities in which patients lived. The socioeconomic features of dialysis patients' home environments may better capture the environmental exposures associated with patients' access to kidney transplant.

This paper describes a quantitative study designed to measure associations between neighborhood-level socioeconomic characteristics of dialysis patients' physical, social, and service environments and kidney transplant wait-listing rates. We hypothesized that ESRD patients living in neighborhoods with more socioeconomically disadvantaged physical, social and service environments would have reduced kidney transplant waitlisting rates compared to patients living in less disadvantaged communities, after controlling for individual-level factors.

## II. Methods

### Data Sources

This quantitative study applied a retrospective cross-sectional research design integrating patient-level and neighborhood-level data from three secondary data sources. The first data set contained dialysis clinic electronic medical records (EMR) from each of this study's three hospital-operated dialysis sites. Dialysis clinic EMR data contained patient-level demographic

and clinical data, street addresses and socioenvironmental information. These data were collected by clinic healthcare providers and staff members from February 2010 (when the dialysis clinics opened) through September 2016 (the end of our observation period). A second data source was the United States Renal Data System (USRDS) dataset, which provided patients' health insurance and waitlisting information last reported in December 2016. The third source was data from the 2011-2016 American Community Survey (ACS), which annually reports sociodemographic findings from U.S. Census Bureau-administered surveys administered randomly to sampled subpopulations (United States Census Bureau/ American Fact Finder, 2016). Data were pooled over 5 years and collected at the census tract-level. The ACS dataset provided neighborhood exposure variables. This project uses Georgia census tracts as a proxy for dialysis patients' neighborhoods. All patient-level data were linked with census tract-level data by patients' last reported residential home addresses. The Emory Institutional Review Board (IRB) has granted this project approval for accessing all patient-level data. Census tract-level data collected from the ACS is publicly available. A description of the variables contained in each dataset is provided in

*Table 2.1: List of Study Variables by Dataset*

<b>Table 2.1: List of Study Variables by Dataset</b>
<b>Dialysis Facility Electronic Medical Record (2010-2016)</b>
Patient Demographics <ul style="list-style-type: none"> <li>• Age</li> <li>• Sex</li> <li>• Race</li> <li>• Lives alone</li> </ul> Patient Clinical data <ul style="list-style-type: none"> <li>• Treating Clinic</li> <li>• Dialysis treatment modality</li> <li>• ESRD Etiology</li> <li>• First dialysis treatment date</li> </ul>
<b>United States Renal Data System Dataset (2016)</b>
Patient Demographics <ul style="list-style-type: none"> <li>• Insurance status</li> </ul> Patient Outcome Data <ul style="list-style-type: none"> <li>• Waitlisting status</li> <li>• Waitlisting date</li> </ul>
<b>U.S. Census Tracts (2010), American Community Survey (2011-2016)</b>
Neighborhood Socioeconomic Exposure <ul style="list-style-type: none"> <li>• Housing unit vacancy rates (physical environment)</li> <li>• Medical uninsured rates (service environment)</li> <li>• Single parent household data (social environment)</li> </ul>

### Study Population

A total of 2,088 adult dialysis patients, 18 years and older received dialysis care from one of the three hospital-owned dialysis clinics located in the Atlanta, Metropolitan area between February 2010 and September 2016. Patients were excluded from this study if their home address was missing (n=378), listed as a P.O. Box (n=9) or located outside of the state of Georgia (n=400). Patients were also excluded from the study if they were waitlisted for a kidney transplant prior to the beginning of this study's observation period (n=142) or if they did not

have a recorded USRDS identification number (n=41). The final study population included 1,118 dialysis patients.

### Outcome Variable

This study's primary outcome variable was time to waitlisting for kidney transplant. This variable describes the number of days patients spent on dialysis during our study period (February 2010 to December 2016) before being added to the kidney transplant waiting list for the first time. Outcome variables were created using dialysis start dates reported by the dialysis clinic EMR dataset and waitlisting dates from the USRDS dataset.

### Exposure Variables

Three neighborhood-level exposure variables were operationalized to be indicators of socioeconomic disadvantage in the physical, social and service environments (Kirby & Kaneda, 2005). Socioeconomic characteristics of the physical environment were captured by home vacancy concentration, described by the percent of housing units that were unoccupied. The service environment was measured by the percent of adults ages 18 to 64 who lacked health insurance. To describe the social environment, a single-parent family variable assessed what percentage of family households with children younger than 18 years were managed by single parents. All three exposure variables were collected from the ACS dataset using census-tract as a proxy for neighborhood (Table 2.1).

### Patient-level Covariates

Several patient-level demographic and clinical variables were collected from the dialysis center EMR. Demographic variables include patients' age at dialysis start (in years), race (white, black or AA, or other), sex (male or female) and last recorded home address. Clinical data captured patients' primary ESRD cause (diabetes, hypertension, or other) and the name (clinic 1,

clinic 2 or clinic 3) and street address of their treating dialysis clinic. Dialysis EMR also provided dates of patients' first dialysis treatments and of deaths, when appropriate. These dates were used to calculate a variable measuring patients total time on dialysis (in days) prior to wait listing, death, or the end of the study period.

Three individual-level SES control variables were separately identified for each of the three neighborhood-level exposure variables to adjust for patient's socioeconomic characteristics linked to the physical, social and service environment. Because patients can receive dialysis in a dialysis clinic or at home, an indicator variable (in-center vs. home-dialysis) was created as patient-level control for the physical environment. Patients approved for home-dialysis tend to have higher SES home characteristics because they must verify that their homes have adequate space for storage supplies and clean space for performing treatments, at a minimum.

Additionally, patients who are more intent on working often pursue home-dialysis because it can take place at night when a person sleeps. Medical insurance status (Medicare, Medicaid, private, uninsured or other) is a variable collected from the USRDS dataset to describe patients' medical insurance status when they began dialysis. This variable is an indicator of patients access to the healthcare services. A binary "lives alone" variable (yes or no) was collected from the dialysis center EMR data as a control variable for patients' social environment. This variable is an indicator of patients' family composition and social support at home.

### III. Data Analysis

#### Geospatial Data Analysis

Geospatial data analysis was conducted to describe the neighborhood-level socioeconomic characteristics of the communities in which dialysis patients lived. The ArcGIS World geocoding service was used to geocode 1118 patient home addresses with 3 hospital-

owned dialysis clinics onto a 2010 Census Bureau map of Georgia census tracts. Next, patient home addresses were spatially joined with their respective census tracts and census-tract data. Spatial analysis was used to obtain distance (in miles) from the patients' homes to their treating dialysis clinic. Geospatial data were analyzed, created, and managed using ArcGis 10.6.1 software.

### Descriptive Data Analysis

Univariate analysis was conducted for all patient and neighborhood-level variables. Frequencies, means, and cross-tabulations were used to describe variable distributions and identify missing data and possible outliers. We calculated means and standard deviations (SD) for neighborhood-level rates of vacant homes, medically uninsured residents and single-parent families, stratified by patient-level characteristics. Bivariate analyses were performed to compare relationships between study variables using correlations, t-tests and ANOVA for continuous variables and chi square tests for categorical variables.

Next, unadjusted relationships between neighborhood socioeconomic disadvantage and waitlisting outcomes were examined. For each of the three neighborhood exposure variables (home vacancy, single-parent families, and uninsured residents), mean values were calculated separately for waitlisted and not-waitlisted patients. Independent-sample t-tests were conducted to compare unadjusted means and assess for significant differences by waitlisting status.

### Cox Proportional Hazards Modeling

Prior to conducting cox modeling to further explore associations between neighborhood-level exposures and wait listing, preliminary analyses assessed the proportional hazard assumption. Graphical Kaplan-Meier methods were used to estimate unadjusted "log-log" survival curves for time to waitlisting for each variable. Additionally, product terms with

interactions between each variable and time were created and statistically examined for significance. Lastly, goodness of fit tests were conducted for covariates using Schoenfeld residuals to evaluate correlations between kidney transplant events and time. Variables that did not meet the proportional hazard assumption were not included in analysis.

To describe the extent to which exposures to neighborhood-level socioeconomic disadvantage were associated with variation in waitlisting after controlling for individual characteristics, time to event analyses were performed using multivariable cox proportional hazard modeling. Patients were censored at death or at the end of the study period (December 31, 2016). Patients with waitlisting dates preceding dialysis start date were given a time-to-event of 1 day. A robust sandwich covariance matrix estimate was used for all models to account for intracluster dependence due to patients living in the same census tracts (E. W. Lee, Wei, Amato, & Leurgans, 1992).

Sequential cox models estimated variations in waitlisting rates separately by the three neighborhood exposure variables. A null model containing only the study outcome was developed to provide baseline estimates for assessing model fit. Next, unadjusted models (Model 1) were created separately for each of the three neighborhood exposure variables by adding the appropriate exposure to the Null Model. In Model 2, all individual-level demographic and clinical covariates (age, sex, race, time on dialysis, treating facility, and etiology) were added to each Model 1. Finally, in Model 3 one individual-level socioeconomic covariate, corresponding to the neighborhood-level exposure was added to each Model 2. More specifically, a patient in-home dialysis variable was added to the neighborhood home vacancy model. A patient insurance status variable was added to the neighborhood uninsured rate model, and individual “lives-alone” status was added to the neighborhood single-parent status.



All statistical analyses were completed using SAS 9.3 statistical software. A p-value of 0.05 or less was used as the criterion for statistical significance in all analysis.

#### IV. Results

A total of 1118 dialysis patients, living in 383 census tracts were included in the study. Patients had a mean age of 55 years ( $SD=14.9$ ) and were mostly African American (88%), and male (56%). Few patients reported being employed either full time (9%) or part time (2%). Most patients were unmarried (65%) although few patients lived alone (15%). Fourteen percent of patients received in-home peritoneal dialysis treatments, with the remainder receiving hemodialysis treatment modalities at their dialysis clinic. Diabetes (57.0%) was reported as the primary cause of ESRD for the majority of patients. Mean neighborhood-level socioeconomic exposures varied across patient-level characteristics. Overall, patients lived in neighborhoods with mean rates of vacant homes, medically uninsured residents, and single-parent families that were higher than both the Georgia state and U.S. national averages, perhaps due to this being a study sample whose health is compromised. Patient and neighborhood-level characteristics are presented in Table 2.2.

**Table 2.2: Socioeconomic Characteristics of U.S. Census Tracts (2010) reported by U.S. and Georgia Geographical Regions and by Characteristics of Dialysis Patients (n=1118) Receiving Treatment from Three Georgia Dialysis Clinics (2010-2016)**

<b>Geographical Regions</b>			<b>Vacant Homes</b>	<b>Single Parent Families</b>	<b>Uninsured Residents</b>
<b>U.S. Population 2010 Census</b>			12.2%	33.0%	16.4%
<b>GA Population 2010 Census</b>			13.1%	35.0%	22.2%
<b>Study Sample Characteristics</b>	<b>n</b>	<b>%</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>
<b>All Study Participants</b>	1118	100%	16.79 (9.22)	56.47 (23.20)	25.38 (10.59)
<b>Age Groups</b>					
<b>18 – 44 years</b>	290	25.94%	17.66 (9.78)	57.25 (22.00)	26.59 (11.56)
<b>45 – 64 years</b>	527	47.14%	16.62 (9.00)	57.06 (22.98)	25.35 (10.13)
<b>65 or older</b>	301	26.92%	16.27 (9.03)	54.66 (24.61)	24.29 (10.33)
<b>Race</b>					
<b>Black</b>	983	87.92%	17.55 (9.17)	59.91 (21.66)	25.92 (9.53)
<b>White</b>	118	10.55%	11.75 (7.75)	31.69 (19.49)	21.25 (16.21)
<b>Other</b>	17	1.52%	8.09 (6.66)	29.34 (15.12)	23.04 (13.54)
<b>Sex</b>					
<b>Female</b>	488	43.65%	16.75 (8.94)	56.93 (23.00)	25.36 (10.19)
<b>Male</b>	630	56.35%	16.83 (9.46)	56.11 (23.36)	25.40 (10.91)
<b>ESRD Etiology</b>					
<b>Diabetes</b>	240	21.47%	15.88 (8.29)	55.23 (22.18)	24.66 (10.79)
<b>Hypertension</b>	637	56.98%	17.64 (9.47)	58.51 (23.12)	25.81 (10.18)
<b>Other</b>	241	21.56%	15.49 (9.26)	52.28 (23.84)	24.97 (11.42)
<b>Treating Clinic</b>					
<b>Clinic 1</b>	332	29.70%	14.48 (7.10)	53.95 (19.70)	24.44 (9.21)
<b>Clinic 2</b>	243	21.74%	19.32 (7.88)	65.06 (18.77)	27.65 (8.21)
<b>Clinic 3</b>	543	48.57%	17.09 (10.52)	54.17 (25.93)	24.95 (12.10)
<b>Dialysis Modality</b>					
<b>Home-Dialysis</b>	160	14.31%	17.40 (9.25)	58.21 (23.02)	25.78 (10.23)
<b>In-Center</b>	958	85.69%	13.18 (8.24)	46.01 (21.52)	23.00 (12.34)
<b>Lives Alone</b>					
<b>No</b>	945	84.53%	18.32 (8.96)	61.17 (25.22)	25.81 (11.17)
<b>Yes</b>	173	15.47%	16.52 (9.25)	55.61 (22.71)	25.31 (10.49)
<b>Insurance Type</b>					
<b>Private</b>	227	20.30%	14.48 (7.77)	50.63 (21.68)	23.37 (10.90)
<b>Medicare</b>	235	21.02%	16.65 (9.40)	57.35 (24.89)	24.48 (10.42)
<b>Medicaid</b>	292	26.12%	18.53 (10.01)	58.69 (24.09)	26.62 (10.27)
<b>Uninsured</b>	197	17.62%	18.30 (9.97)	61.09 (20.84)	27.91 (10.96)
<b>Other</b>	167	14.94%	15.36 (7.47)	53.81 (22.10)	24.25 (9.77)

Findings from unadjusted t-tests demonstrated that waitlisted patients, compared to patients who were not waitlisted, lived in neighborhood with 16% lower rates of vacant homes (14.74% vs. 17.46%), 14% lower rates of single parent families (50.19% vs. 58.50%) and 16% lower rates of uninsured residents (24.64% v. 25.62%). These differences were statistically significant for vacant homes ( $p<.0001$ ) and single-parent families ( $p<.001$ ) but not for uninsured residents ( $p=0.21$ ) (Table 2.3).

<b>Table 2.3: Socioeconomic Characteristics of U.S. Census Tracts (2010) resided in by Patients (n=1118) of Three Georgia Dialysis Clinics (2010-2016), Reported by Dialysis Patient Waitlisting Status</b>			
<b>Neighborhood Characteristics</b>	<b>Waitlisted Patients n=273</b>	<b>Not Waitlisted Patients n=845</b>	<b>P-value</b>
<b>Vacant Homes % (SD)</b>	14.74% ( $\pm 7.63\%$ )	17.46% ( $\pm 9.60\%$ )	<.0001
<b>Single Parent Families % (SD)</b>	50.19% ( $\pm 23.45\%$ )	58.50% ( $\pm 22.76\%$ )	<.0001
<b>Uninsured Resident % (SD)</b>	24.64% ( $\pm 11.66\%$ )	25.62% ( $\pm 10.22\%$ )	0.21

Among the 1118 patients included in cox modeling, the median follow-up time was 37 months. A total of 273 (24%) patients were wait-listed, 295 (26%) patients died, and 13 (1%) patients received a kidney transplant. A total of 845 patients were censored because they died ( $n=279$ ) or reached the end of the study period ( $n=566$ ) without being waitlisted for transplant.

Results from sequential cox modeling revealed associations between neighborhood-level socioeconomic exposures and waitlisting that maintained over and above patient-level characteristics. Patients who lived in neighborhoods with higher home vacancy rates had a 2% reduced rate of being waitlisted for kidney transplant ( $HR=0.98$ ; 95% CI= 0.97, 1.00;  $p=.01$ ), compared to those living in neighborhoods with lower home vacancy rates. Similarly, residents of neighborhoods with higher concentrations of single-parent families showed a 1% decreased waitlisting rate ( $HR= 0.99$ ; CI=0.99, 1.00;  $p=.01$ ), compared to individuals from neighborhoods

with less single-parent families. These relationships were attenuated by but remained statistically significant after adjusting for patient-level characteristics. Living in a neighborhood with a higher rate of medically uninsured residents was not associated a lower waitlisting rate (HR=0.99; 95% CI=0.98, 1.00; p=0.4) compared to residing in a community with less uninsured residents. Results from sequential cox modeling are presented in Table 2.4.

<b>Table 2.4: Multivariate Sequential Cox Modelling Results, Reporting Hazard Rates for Kidney Transplant Waitlisting (2010-2016) Associated with Variation in Dialysis Patients' (n=1118) 2010 U.S. Census Tract Socioeconomic Characteristics</b>						
<b>Model</b>	<b>Vacant Homes</b>		<b>Single-Parent Families</b>		<b>Uninsured Residents</b>	
	HR (95% CI)	-LogL	HR (95%CI)	-LogL	HR (95%CI)	-LogL
<b>Null</b>	---	3641	---	3641	---	3641
<b>Model 1</b> ( <i>Null Model</i> + <i>Neighborhood Exposures</i> )	0.96 (0.95, 0.98) ***	3617	0.98 (0.98, 0.99) ***	3609	0.99 (0.98, 1.00)	3638
<b>Model 2</b> ( <i>Null Model</i> + <i>Individual Covariates</i> )	0.98 (0.96, 0.99) **	2939	0.99 (0.99, 1.00) *	2939	0.99 (0.98, 1.00)	2945
<b>Model 3</b> ( <i>Model 2</i> + <i>Individual SES controls</i> )	0.98 (0.97, 1.00) *	2932	0.99 (0.99, 1.00) *	2931	0.99 (0.98, 1.00)	2907
<b>Note: *p&lt;.05, **p&lt;.001, ***p&lt;.0001</b>						

## V. Discussion

Understanding neighborhood-level socioeconomic factors associated with reduced access to healthcare is essential to improving kidney transplant rates for ESRD patients in the U.S. This study of 1118 predominantly African American prevalent dialysis patients was designed to measure associations between neighborhood-level socioeconomic characteristics of dialysis patients' physical, social, and service environments and kidney transplant wait-listing rates. We

hypothesized that ESRD patients living in neighborhoods with more socioeconomically disadvantaged physical, social and service environments would have reduced kidney transplant waitlisting rates compared to patients living in less disadvantaged communities, after controlling for individual-level factors. In support of our hypothesis, we found that patients who lived in neighborhoods with higher concentrations of vacant housing and single-parent families were less likely to be waitlisted for kidney transplant. Adjusted cox modeling showed that these relationships remained statistically significant for vacant housing and single-parent families after controlling for patient-level demographics, ESRD etiology, treating dialysis facility and socioeconomic characteristics. Findings related to vacant housing and single-parent families align with previous studies that found living in low SES neighborhoods to be associated with increased risk for poor ESRD outcomes (Johns et al., 2014; L. Plantinga et al., 2014; Saunders, Cagney, Ross, & Alexander, 2010). Results describing the relationships between higher neighborhood rates of medically uninsured residents and patient waitlisting, however, were not statistically significant.

### Physical Environment

Findings that suggest higher rates of home vacancies are associated with reduced transplant waitlisting support previous study findings that describe links between increased home vacancies rates and poorer health (D. Cohen et al., 2003; Garvin, Branas, Keddem, Sellman, & Cannuscio, 2013; Wang & Immergluck, 2018). Neighborhoods with high concentrations of home vacancies may adversely impact waitlisting rates for dialysis patients by limiting access to valuable transplant-related community resources including social support and healthcare services (D. Cohen et al., 2003; Wang & Immergluck, 2018). For example, high home vacancy rates are associated with population decline and housing instability which may limit interactions

between neighbors and make it difficult for patients to maintain social relationships (D. Cohen et al., 2003). High home vacancy rates are also associated with reduced social infrastructure and fewer healthcare services (Cui & Walsh, 2015; Han, 2014; Wang & Immergluck, 2018) which can create barriers to accessing transplant-related health services. Additionally, high concentrations of unoccupied homes may contribute to higher neighborhood crime which can impede transplant pursuit by inducing stress and making patients feel unsafe performing healthy behaviors, such as taking public transportation (Cui & Walsh, 2015; Garvin et al., 2013).

### Social Environment

Results related to single-parent families build upon findings by Plantinga et al. (2014) .which describe moderate associations between higher concentrations of single-mothers living in dialysis facility census tracts and reduced kidney transplant rates. On average, single-parents attain less education have lower household incomes compared to married parents. Links between single parenting and lower SES characteristics are complex but may be largely attributed to these families having fewer adults earning incomes to support the household and less assistance with childcare. Additionally, the vast majority (82%) of single-parent families are managed by mothers who may face additional financial barriers due to gender-based income and employment inequalities (U.S. Census Bureau, 2016). Living in communities with high concentrations of single-parent families may expose patients to weaker social cohesion and to social networks that have fewer resources for instrumental support.

### Service Environment

Study results related to the service environment revealed effect sizes that supported an inverse relationship between neighborhood uninsured concentrations and waitlisting rates but were not statistically significant in any of the analyzed sequential cox models. Findings from this

study suggest that neighborhood-level insurance rates play a lesser role in shaping dialysis patient access to transplant than other community features. This result diverges from previous study findings which support links between neighborhood uninsured rates and access to healthcare for other patient populations (Garfield & Damico, 2016; Kirby & Kaneda, 2005). Among other study populations, lower community uninsured rates may impact individual healthcare access by promoting healthier norms and information sharing that encourage healthcare utilization (Kirby & Kaneda, 2005). However, community norms related to healthcare utilization may be less important for shaping dialysis patients access to transplant. This study variable may perform differently among dialysis patients than other populations because they are in the final stages of a progressive chronic kidney disease. Patients with ESRD are sicker than the general population and require costly dialysis treatments or even more expensive transplant surgeries to survive (United States Renal Data System, 2018). While beyond the scope of this project, it is possible that community insured rates have stronger associations with patients access to healthcare at earlier stages of chronic kidney disease.

Results showing the attenuating effect of patient characteristics on the relationship between neighborhood-level socioeconomic disadvantage and waitlisting further support previous studies demonstrating links between individual race, SES, and ESRDS etiology and waitlisting outcomes (Axelrod et al., 2010; Ozminkowski et al., 1998; Patzer & McClellan, 2012). This project controlled for individual-level SES characteristics to provide stronger evidence of the relationship between neighborhood level exposures and access to transplant. Some previous studies have not had access to such data (Johns et al., 2014).

This project examined three meaningful socioenvironmental factors and their associations with kidney transplant waitlisting. This approach builds upon studies that have primarily

examined links between neighborhood poverty rates and transplant-related outcomes (Johns et al., 2014; Patzer et al., 2009). Findings from these studies have supported links between higher neighborhood poverty rates with decreased kidney transplant waitlisting (Patzer et al., 2009) and increased mortality risk (Johns et al., 2014). Poverty rates are one of many ways of describing community SES. However, by exploring aspects of patients physical, social, and service environments, this project identifies exposures to socioeconomic disadvantage that may better describe the pathways by which socioeconomic inequalities shape ESRD patients' health and access to care

Findings showed small effect sizes for both neighborhood home vacancy rates and single-parent families suggesting that these are one of many factors associated with patients access to transplant. Future studies should seek to identify other characteristics of the physical, social and service environments that shape access to transplant.

This study's design is not without limitations. This study's cross-sectional design limits opportunities for assumptions of causality between neighborhood-level socioeconomic disadvantage and waitlisting. However, research described by Adler and Ostrove (1999) support causal pathways by which socioeconomic characteristics of patients' external environments are determinants of healthcare access and health outcomes (Figure 1.4).

We used convenience sampling methods to identify ESRD patients who lived in a narrow geographic region and most patients lived in communities with poorer SES characteristics than state and national averages, thus limiting the generalizability of our findings. Patients were excluded if they were missing data essential for conducting data analysis including USRDS IDs and patient addresses. While necessary, the exclusion of these participants increases concerns of selection bias.



In addition to these limitations, patients home addresses were collected from a secondary dataset providing their most recently reported address. This approach assisted us in identifying the address patients reported living at while on dialysis during the study period but does not account for multiple residences patients could have had if they relocated any time during the study period. Patient addresses also do not account for how long patients lived in their homes. Examining fluctuation in neighborhood addresses and environmental exposures before and during the study period was beyond the scope of this project. However, future projects should consider this work as it could enhance knowledge about the impacts of neighborhood socioeconomic conditions over time.

Our study sample is a prevalent cohort of dialysis patients who had never been waitlisted for kidney transplant. While all patients received dialysis care from one of our three study dialysis clinics during the observation period, some patients began dialysis prior to February 2010. To partially account for differences in dialysis initiation, we controlled for total years on dialysis. Still, differences in dialysis onset is a limitation because it increases the likelihood that patients who have been on dialysis longest could have secular exposures related to waitlisting outcomes for which this study cannot account.

Study findings supporting relationships between high rates of vacant homes and single parent families and reduced waitlisting rates have meaningful implications for promoting equitable access to kidney transplant. Study results demonstrate the importance of dialysis clinics and transplant centers staff being aware of the community contexts in which patients live. Patients who live in communities with more vacant homes or single parent families (regardless of their individual SES) may benefit from receiving additional resources to compensate for resource limitation in their home neighborhoods. For example, psychological counseling

provided to patients in dialysis facility settings have demonstrated success in improving mental health outcomes and increasing relationship satisfaction and may be useful for patients who live in poorer physical or social environments (Rodrigue, Mandelbrot, & Pavlakis, 2011). This type of intervention may be important for helping patients manage stress induced in high crime communities or to develop tools for sustaining network connections. More research is needed to elucidate how dialysis patients' experiences in communities with high rates of home vacancies and single-parent families are related to access to transplant to develop effective interventions that improve transplant-related outcomes.

Findings from this study also harken the need for interventions that reach beyond the individual-level. One approach is to implement policy interventions that better support single-parent families and address vacant housing to improve the resources available to transplant recipients. For example, programs that provide affordable early childcare have demonstrated success in improving employment rates among single parents and may increase the resources available within their communities (Morrissey, 2017). Regarding housing vacancies interventions have demonstrated success in improving community physical environments by demolishing, beautifying, or repurposing vacant buildings to improve neighborhood conditions (Pruett, 2014).

Improving access to kidney transplant for dialysis patients living in poorly resourced communities may also require large-scale policy changes. Link and Phelan (1996) maintain that effectively reducing disparities in healthcare access will, first, require eliminating higher level policies that institutionalize social inequalities. Socioeconomic inequality is institutionalized in the Kidney Allocation System through policies that require patients to demonstrate their ability to afford a kidney transplant before they are added to the waitlist. Improving equitable access to

kidney transplant will requires that patients who have lower SES or who live in less resourced environments be connected to resources rather than begin excluded based on these limitations.

This study highlights the importance of neighborhoods settings in understanding dialysis patient's access to transplant. Findings suggest that contexts and compositions of patients' home communities may facilitate or constrain access to transplant above and beyond their personal characteristics (Glass & McAtee, 2006). Study findings encourage research that further identify strategies for promoting equitable access to kidney transplant.

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## Chapter Three - Social Network Functions and Kidney Transplant Pursuit

A qualitative study exploring African American dialysis patients' social network functions associated with pursuit of kidney transplant in Atlanta, Georgia.

### I. Introduction

End-stage renal disease is a chronic condition characterized by kidney failure. Individuals diagnosed with ESRD must either receive routine dialysis treatments to mechanically carry out the kidney's role of filtering the blood or undergo kidney transplant surgery to replace the poorly functioning organ with a donor organ (National Institute of Diabetes and Digestive and Kidney Diseases, 2013).

Kidney transplant is the recommended therapy for many patients with ESRD. Patients who receive kidney transplant transplants have experience increased life expectancy, reduced hospitalization and improved quality of life, compared to ESRD patients who receive ongoing dialysis treatments (Southeastern Kidney Council, 2014; Tonelli et al., 2011). Unfortunately, low transplantation rates are observed among ESRD patients in the U.S. where donor organ supplies are insufficient to meet the national need (United States Renal Data System, 2018).

The standard pathway for pursuing a kidney transplant involves a set of progressive steps which begin with ESRD diagnosis and lead to kidney transplant surgery. Receiving a kidney transplant from a deceased donor requires that patients obtain adequate transplant education, express interest in receiving a transplant, be referred to a transplant center by a kidney specialist, complete an extensive evaluation process at a transplant center, and become waitlisted on the national organ registry until they are matched with a compatible organ through the Organ Procurement and Transplantation Network's (OPTN) Kidney Allocation system (see Figure 1) (R. Patzer, Plantinga, Krisher & Pastan, 2014). The pathway to successful living donor kidney

transplantation is the same except that individuals would not need to be matched with an organ from the kidney allocation system.

African American ESRD patients are disproportionately less likely to receive a kidney transplant and have 30% lower kidney transplant rates than white ESRD patients (Patzner & Pastan, 2014; United States Renal Data System, 2018). Factors that contribute to inequities in AA kidney transplantation rates exist at various levels of the social ecological model and are attributed to racial inequities across the transplant pathway (Glass & McAtee, 2006). For example, at an individual level, research suggests that AA dialysis patients often have lower kidney transplant knowledge (Kucirka et al., 2011) and have greater concerns about being unable to afford the costs of transplant and post-transplant care compared to whites (Ganji et al., 2014), which may deter AA ESRD patients from seeking a kidney transplant. At the interpersonal level, patients with more supportive social networks (Heaney & Israel, 2008; House, 1981), have greater success in navigating the transplant pathway and increased access to kidney transplant (Arthur, 2002; Browne, 2011). At the community level, neighborhood poverty is associated with adverse health outcomes, including lower than expected transplantation rates for AAs living in poor neighborhoods compared to those living in wealthier neighborhoods (Patzner et al., 2009). While the factors associated with disproportionately low AA kidney transplantation rates exist at various socioecological levels, this paper focuses on interpersonal and community-level factors to explore how patients' social networks function to facilitate or impede kidney transplant pursuit.

Existing literature suggest that social networks, defined by the collections of overlapping connections between people (Heaney & Israel, 2008; House, 1981), play a critical role in AA patients' pursuit of transplant. More supportive networks are linked to greater success in

navigating the transplant pathway and increased access to kidney transplant (Arthur, 2002; Browne, 2011; K Ladin et al., 2019).

Four key functions of social networks that impact health behavior are social influence, social undermining, social companionship, and social support. Social influence refers to ways that the actions of others affect individuals' beliefs and behaviors (Bartholomew, Parcel, & Kok, 1998; Heaney & Israel, 2008). Social undermining describes individuals' health behavior goals being impeded by others' actions or expressed criticisms (Heaney & Israel, 2008; House, 1981). Companionship refers to the time spent with other individuals within the network. Social support describes the ways social network members assist individuals with performing health behaviors and can be organized into four sub-categories, including 1) emotional support offering empathy, love, trust, and caring, 2) instrumental support extending tangible assistance and services, 3) Informational support offering advice, suggestions, and knowledge about a problem, and 4) appraisal support providing constructive feedback, affirmation, and information that guide self-evaluation and decision-making (Heaney & Israel, 2008; House, 1981).

Lower than expected kidney transplantation rates observed among AA ESRD patients may be partially explained by the prevalence of social networks that lack key resources for navigating the transplant pathway or for demonstrating patients' eligibility for the transplant waiting list. Brown and colleagues (2011) surveyed 228 AA patients in Chicago and found that dialysis patients were more knowledgeable about kidney transplant if they had larger social networks. Additionally, patients whose networks included people with higher incomes and members who shared more information about transplant had more accurate transplant knowledge, compared to individuals with lower income and less information-sharing networks (Browne, 2011). Another study conducted by Clark and colleagues with 742 AA and white

American participants across the U.S. found that patients who accessed more tangible support from their social networks are more successful in completing the transplant evaluation, compared to patients with less support (Clark et al., 2008). Strong social networks may also be a critical component of meeting eligibility requirements for transplant during the evaluation process given that transplant centers commonly require patients to demonstrate having a strong social or family support system (Emory Healthcare Kidney Transplant Program, 2016). While stronger social networks are linked to increased access to kidney transplant, AA dialysis patients are more likely to have weaker networks that are more dense, homogenous and limited in resources needed to pursue kidney transplant, compared to white American patients' networks (Browne, 2011). These limitations suggest that many AA dialysis patients lack social networks with the capacity to function in promoting their progressive steps through the transplant pathway (United States Renal Data System, 2018).

Not enough is understood about AA dialysis patients' social networks and how they function to influence kidney transplant pursuit. Studies often focus on transplant-related social support while largely understudying the impact of other roles of social networks, both positive and negative (Lunsford et al., 2006; Rodrigue, Cornell, Kaplan, & Howard, 2008). For example, recent studies have made valuable contributions to literature by establishing associations between increased informational support and important transplant outcomes, including the willingness to ask for an organ donation from a living donor (Rodrigue et al., 2008). Other studies have emphasized ways that social networks provide instrumental social support for ESRD patients' transplant pursuit (Clark et al., 2008). However, not all roles of social networks are positive. In particular, social undermining remains an underexplored network construct among dialysis patients considering kidney transplant, despite evidence that various forms of

social undermining, such as criticism and mistrust from network members are linked to poor health outcomes and risky health behaviors within other health topics (Fleishman et al., 2000; Heaney & Israel, 2008). Ladin and Hanto (2010) further attest to the tendency for existing social network literature to focus on social support when exploring factors impacting kidney transplant pursuit and identify the need for more comprehensive research exploring how other roles of social networks influence kidney transplant.

Research is also needed that facilitates a more in-depth understanding of the relationship between social network functions and ESRD patients' interest and pursuit of kidney transplant. Existing studies commonly use single-item survey questions to ask about complex topics such as instrumental support (Clark et al., 2008), which may be better suited for more detailed indices or qualitative methods.

This paper builds upon existing literature by using qualitative methods to answer the following research questions: 1) How are functions of social networks (i.e. social influence, social undermining, social companionship, and social support) experienced by AA in-center hemodialysis patients? and 2) In what ways are AA hemodialysis patients' social network functions associated with pursuit of kidney transplant? Findings from this research will be useful for providing recommendations for dialysis clinic, transplant center, and broader renal healthcare system policies and interventions aimed to improve AA ESRD patients' access to kidney transplant.

## II. Methods

This project involved semi-structured in-depth key informant interviews in-person with 37 AA ESRD patients receiving hemodialysis treatments at three hospital-owned dialysis clinics in Atlanta, Georgia. A qualitative exploratory design was applied to capture descriptive details

about patients' dialysis experiences, social network functions and perspectives on pursuing a kidney transplant (Hsieh & Shannon, 2005; Salazar, Crosby, & DiClemente, 2011)

### Participant Selection and Setting

Patients were eligible for participation if they currently received in-center hemodialysis treatments and were between 21 and 60 years old. Patients had to have been on dialysis for at least six consecutive months at the time of study enrollment and self-identify as Black or AA. They were recruited at one of three non-profit, hospital-owned dialysis centers located in metropolitan Atlanta, Georgia. Recruitment flyers containing study details and contact information were posted in dialysis clinic patient areas and distributed to patients by clinic social workers and the principal investigator. Patients interested in participating in the project were screened for eligibility and enrolled by the principal investigator. Quota sampling was used to ensure that the study sample varied by dialysis clinic, referral status and gender. Across the three dialysis clinics, 19 women (10 referred for transplant, 9 not referred for transplant) and 18 men (9 referred for transplant, 9 not referred for transplant) were enrolled for a total of 37 study participants. Emory's Institutional Review Board (IRB) granted approval for this study (IRB00096498).

### Data Collection

We recruited, enrolled and interviewed dialysis patients over a three-month period from June to August 2017. Thirty-seven semi-structured in-depth interviews were completed in-person during patient' dialysis treatments. Written informed consent was obtained from all study participants prior to participation. We collected supplemental patient data using a brief electronic survey and by reviewing each patient's medical chart to confirm clinical information related to their treatment.

## Measures

The study team developed a structured interview guide with assistance from a nephrologist and social worker from the dialysis clinics. Several interview items were adapted from the validated National Health and Social Life Social Network survey (Laumann, Gagnon, Michael, & Michaels, 2008) and by Browne's (2011) survey items developed to explore the relationship between social network characteristics and pathways to kidney transplant parity in Chicago, Illinois. The interview guide contained simple, open-ended questions and prompts for patients to describe their 1) health progression from kidney disease to ESRD, 2) interest in and pursuit of kidney transplant, 3) social network functions (social influence, social undermining, social companionship, social support), 4) life before dialysis and 6) life on dialysis. Interviews lasted an average of 62 minutes ( $SD=19.8$ ) and were audio-recorded in entirety using a digital recorder.

Following the interview, additional patient data were collected using a brief electronic survey and a medical abstraction form. The electronic survey collected information on patient demographics, kidney transplant pursuit and social network connections. Demographic questions asked participants to share their age, gender, marital status, and race/ethnicity. Survey items related to kidney transplant pursuit included two questions. First, participants answered the question, "How interested are you in pursuing a kidney transplant?" Response options were "Very interested", "Somewhat interested", "Neutral", "Not very interested", or "Not at all interested." Second, participants answered the question, "Would you undergo kidney transplant if you are given a chance when the time comes?" by responding "Yes" or "No." Survey items related to social network connections were adapted from a validated Social Network Index (S. Cohen, Doyle, Skoner, Rabin, & Gwaltney, 1997). Questions asked patients to identify the

number of people they spent time with in the past two weeks from various network categories (e.g. immediate family, extended relatives, friends, faith communities, community organizations, and work settings)

The medical abstraction form collected data on patients' demographics, ESRD progression and transplant wait-listing status. ESRD progression items included questions about patients' initial dialysis start date, transplant center referral status, and transplant waitlisting status. Study participants were given a \$30 cash incentive after completing the interview and survey.

### III. Data Analysis

Audio recordings of interview sessions were transcribed verbatim by the principal investigator and an Emory University graduate assistant to ensure accuracy. Transcripts were uploaded into Atlas.ti. Systematic qualitative analyses were employed into transcription, codebook development and iterative coding (Creswell & Plano Clark, 2007). A preliminary codebook manual was developed by using the nested themes from the interview guide to name key codes in interview transcripts. The study team revised the preliminary codebook in a collaboration meeting to ensure the codes were appropriate to capture participants descriptions of their social networks and their thoughts and experiences related to kidney transplant pursuit. A total of 73 codes were identified, nested within 11 code families.

The principal investigator coded all transcripts using the revised codebook. To strengthen study reliability, the principal investigator discussed sample quotations for each code with a study team member after coding the first transcript to achieve consensus on how codes would be applied. Exploratory qualitative methods were applied to analyze interview data using a deductive process to describe the interview guide domains. Analyses also confirmed and



expanded upon a theoretical assumption that that the four social network functions were related to pursuit of kidney transplant. (Hsieh & Shannon, 2005; Patton, 2002; Salazar et al., 2011).

Study findings emerged from persistent themes and prevalent data trends identified in the coded qualitative transcripts. Findings were used to answer study-related research questions.

#### IV. Results

We analyzed data from 37 AA hemodialysis patients. Participants were adults with ages between 27 and 60 years (Mean=49, SD= 8). Most participants completed high school or a GED (86%), while 16% completed college or more advanced degrees. Interviewed patients were mostly single (70%) and nearly half had incomes less than \$10,000 per year (49%). Almost all patients received Medicare (97%), with slightly fewer also receiving Medicaid (70%) (Table 3.1). Social networks were mostly comprised of close ties with relatives, friends and church members identified as the network members. Looser connections often included dialysis clinic patients and staff members.

<b>Table 3.1: Characteristics of Patients (n=37) Receiving Care from Three Georgia Dialysis Clinics, Reported by Sex and Transplant Center Referral Status</b>					
<b>Participant Characteristics</b>	<b>All n=37</b>	<b>Female Participants</b>		<b>Male Participants</b>	
		<b>Referred n=10</b>	<b>Not Referred n=9</b>	<b>Referred n=9</b>	<b>Not Referred n=9</b>
<b>Mean Age (SD)</b>	49 (8)	47 (8.2)	49 (12.8)	48 (4.3)	52 (4.2)
<b>Mean Years on Dialysis (SD)</b>	7 (6)	6 (3.5)	6 (7.7)	5 (3.4)	10 (8.5)
<b>Education Completed</b>					
<b>Less than high school</b>	5 (14%)	3 (30%)	1 (11%)	0	1 (11%)
<b>High school or GED</b>	17 (46%)	4 (40%)	5 (56%)	6 (67%)	4 (44%)
<b>Some College</b>	9 (24%)	3 (30%)	2 (22%)	0	2 (22%)
<b>Bachelor</b>	5 (13%)	0	1 (11%)	3 (33%)	1 (11%)
<b>Graduate or Professional School</b>	1 (3%)	0	0	0	1 (11%)
<b>Marital Status</b>					
<b>Married or Domestic Partnership</b>	11 (30%)	4 (40%)	1 (11%)	4 (44%)	2 (22%)
<b>Divorced or Separated</b>	13 (35%)	5 (50%)	3 (33%)	2 (22%)	3 (33%)
<b>Never married</b>	13 (35%)	1 (10%)	5 (56%)	3 (33%)	4 (44%)
<b>Income</b>					
<b>Less than 10,000</b>	18 (49%)	6 (60%)	5 (56%)	4 (50%)	3 (33%)
<b>10,000 to 25,000</b>	10 (28%)	2 (20%)	2 (22)	2 (25%)	4 (44%)
<b>25,000 to 50,000</b>	4 (11%)	0	1 (11)	1 (13)	2 (22%)
<b>More than 50,000</b>	1 (3%)	1 (10%)	0	0	0
<b>Prefer not to answer</b>	4 (11%)	1 (10%)	1 (11%)	2 (25%)	0
<b>Health Insurance</b>					
<b>Medicare</b>	36 (97%)	10 (100%)	9 (100%)	9 (100%)	8 (89%)
<b>Medicare Only</b>	2 (5%)	0	1 (11%)	1 (11%)	0
<b>Medicare + Medicaid</b>	26 (70%)	8 (80%)	5 (56%)	7 (78%)	6 (67%)
<b>Medicare + Private</b>	8 (22%)	2 (20%)	3 (33%)	1(11%)	2 (22%)
<b>Not Insured</b>	1 (5%)	0	0	0	1 (11%)
<b>Waitlisted for kidney transplant</b>	6 (16%)	2 (20%)	0	4 (50%)	0

Study findings indicate that participants were mostly willing to pursue kidney transplant despite few participants demonstrating success in progressing to the kidney transplant waiting list. Results from the post-interview electronic survey demonstrated that 81% of participants were willing to get a kidney transplant. Similarly, patients' mean transplant interest score was

4.11 (where 1 = not at all interested, 5 = very interested). However, only half of patients were referred for transplant, and 16% of participants were waitlisted for transplant.

Interview findings revealed participants' willingness to pursue a kidney transplant as complex, dynamic processes, often guided by external forces. Participants frequently described being interested in kidney transplant, so they could become "normal" again and resume life activities (e.g. working full-time, spending time with family). Some participants were confident about wanting a kidney transplant, while other participants expressed uncertainty about their transplant interests because they were still weighing pros and cons. Other patients were unsure about their willingness to pursue transplant because they did not believe they had enough information to make an informed decision regarding transplant. For example, one man wanted to visit another hospital to try an experimental procedure. Another man distrusted the medical recommendations he had received from his doctors and was collecting stories from transplant recipients to better understand the "truth" about what life was like after transplant.

This section describes key themes that emerged from qualitative patient interviews to answer the following research questions:

1) How are functions of social networks (i.e. social influence, social undermining, social companionship and social support) experienced by AA in-center hemodialysis patients?

2) In what ways are AA hemodialysis patients' social network functions associated with pursuit of kidney transplant?

Findings are organized by social influence, social undermining, social companionships and social support. A summary of common themes found in qualitative interview discussions are outlined in Table 3.2.

### Social Influence

Two groups of social network members were commonly identified as influential in encouraging kidney transplant: 1) transplant recipients and 2) family members.

*Transplant recipients.* Most patients (n=22, 61%) identified successful transplant recipients as important in promoting positive perceptions about transplant. Patients typically met transplant recipients at their treating dialysis clinics. Participants described being inspired by the stories of transplant recipients who were once on dialysis like them but were now living with a new kidney. Participants were especially encouraged by transplant recipients' abilities to reengage in daily activities they were unable to continue while on dialysis. When asked about his interactions with transplant recipients, one participant shared this:

**I see the different experiences and I ask [transplant recipients] about, you know, their foods, what they eat how they copin' with it, just to go to work, work a regular job. You know it kinda gives you hope that you can get off of [dialysis].**

*(Man referred for kidney transplant, Age 51)*

Another patient described influential conversations with transplant recipients this way:

**They said you feel great, you feel like a total different person....They said you feel great, like you can eat, and you gain weight...You do, you just do what you used to do...[like] go travel.**

*(Woman referred for transplant, Age 52, 8 years on dialysis)*

For many, hearing positive transplant experiences encouraged interest and action steps toward transplant.

**[Conversations with transplant recipients] made me want it more and more. 'Cause I see the changes it had made in their lives.... Like, for instance, the energy, and you know, gettin' around, being able to do more for their families and stuff like that.**

*(Man referred for transplant, Age 48, 2 years on dialysis)*

Similarly, when asked how conversations with transplant recipients impacted his thoughts about

transplant, another patient shared:

**Yeah, it encourages more, you know. Before I even got approved, I had to take the steps to get approved, so. It motivated me more, you know, it motivated me real more to get approved for [transplant].**

*(Man referred and waitlisted for transplant, Age 39, 3 years on dialysis)*

*Family members.* Family members were another group identified by many patients (n=26, 72%) as influencing their transplant decision-making. Influential family members were usually close relatives such as parents, siblings, spouses and children. Participants described influential gestures from family members to take the form of verbally expressing their desire for them to get a transplant. This was more likely to occur when family members believed having a transplant would increase patients' longevity or quality of life. Younger family members were also influential. Patients who had young children or grandchildren often described them as inspiring them to pursue transplant because when they believed it would allow them to be healthier and more active or live longer for them. One participant said this:

**They the ones that really keep me wantin' to live extensively, cuz I wanna see 'em grow up. I wanna see 'em graduate, I wanna see 'em get married, and have a good life, you know, down the line, and I wanna be a part of that.**

*(Man not referred for transplant, Age 50, 3 years on dialysis)*

Social Undermining

Few patients described encounters with social undermining regarding their interest or pursuit of kidney transplant. When asked about their experiences with people expressing negative opinions about transplant, few patients (n=4, 11%) patients identified people who discouraged their transplant pursuit. Patients more commonly described their intentional efforts to avoid negative conversations about kidney disease. For example, when asked if she could describe any people who discouraged her from pursuing transplant, one patient responded,

**No, because I don't interact with negative people.**

*(Woman referred for transplant, Age 45, 8 years on dialysis)*

Another person expanded upon this thought, sharing,

**When people come on some negative anything, that's, blahblahblah, that's just all I hear, I don't hear nothin' else, I probably look at them stupid, I might say ehheh, you know what I'm sayin', but I don't... I don't listen to that.**

*(Man referred for transplant, Age 39, 3 years on dialysis)*

These efforts to avoid negative conversations about kidney transplant were a consistent theme across patient interviews. Efforts to stay positive about their ESRD and kidney transplant were an important coping mechanism used by many patients to maintain their health and well-being but may have an added benefit of mitigating social undermining.

The four participants who reported encountering social undermining identified conversations with previous transplant recipients and dialysis patients as influential in dissuading their steps towards kidney transplant. Patients reported the most compelling parts of these conversations to be assertions about immunosuppressant medications, medical side effects, and premature death. Conversations about medication were especially concerning to participants.

They feared they would have to take too much medicine or that the side effects of the medication would outweigh the benefits. One man shared this.

**You have to take all the medicine, different meds, the steroids and stuff make you gain weight, swell up and stuff like that. Cuz I got a buddy. He just got a kidney. From the steroids, he look like a balloon.**

*(Man referred for transplant, Age 48, 2 years on dialysis)*

Other participants described hearing that undergoing transplant could cause other diseases such as cancer or increase their risk of premature death. One person said this.

**They say that if you get a kidney you gonna die. That's what they sayin'. They sayin' that when people get a kidney they die quicker.**

*(Woman not referred for transplant, Age 52, 4 years on dialysis)*

### Social Companionship

Interview conversations related to social companionship most often identified small circles of close family members and dialysis clinic patients and staff as the social network members with whom participants spent quality time in the two weeks prior to being interviewed. Descriptions about companionship and the barriers and facilitators to maintaining relationships provide a better understanding of who dialysis patients have present when they are making decisions about or actively pursuing kidney transplant.

*Family members.* Family companions were most often immediate relatives including parents, siblings, children and grandchildren who lived locally. Bonds with family members were commonly identified as participants' most important and accessible social connections. In many instances, patients lived with immediate family members. Patients expressed wanting family present if they were to receive a kidney transplant.

**I don't know, I feel like I'm a big boy but everybody need somebody to kinda like, be there at some point and I think [having a kidney transplant] would be a situation where I'm gonna need my mom.**

*(Man referred for transplant, Age 51, 3 years on dialysis)*

*Dialysis clinic patients and staff.* Other resources for companionship described by participants were patients and staff members at the dialysis clinic. The dialysis center was one of the few sources for new social connections, established after initiating dialysis. Patients described the people they met at the clinic as feeling like “family.”

**It's just like family. I mean, everybody in here, we didn't know each other, now we know each other. A lot of the workers, you know, they really are. They take care of us, and we appreciate it.**

*(Woman referred for transplant, Ager 45, 8 years on dialysis)*

Another participant shared this:

**[They] showed me it's gonna be alright and let me know I'm not in it, I'm not in it by myself, we all goin' through the same situation or the same, we in the same predicament.**

*(Man referred for transplant, Age 48, 8 years on dialysis)*

For some patients, the dialysis center was the only resource for companionship. One participant reported this.

**There some people that come here, they don't have nobody to talk to, they be glad to come in here, they can get they laugh and be happy, and be around for three days a week, but other than that, they don't have nobody to talk to. A lot of people come here for that, you know.**



*(Man not referred for transplant, Age 54, 14 years on dialysis)*

*Barriers to companionship.* Although discussions consistently identified family members and dialysis patients as primary resources for social companionship, they also acknowledged several barriers to spending quality time with companions during their time on dialysis when kidney transplant is often considered. For example, most patients felt that the hours spent traveling to and from the clinic and receiving dialysis treatments three days a week limited the time they could spend with family. Feeling sick or tired after treatments and having travel limitations were two additional challenges to participating in activities with family members. For example, one participant described having to sometimes cancel plans with his daughter if he did not feel well after his treatment.

**Like on the days I do dialysis if somebody want to do something I have to be like, wait, you know wait until tomorrow, or wait until later. Cuz it's the same thing, the other day, my daughter wanna come pick me up to go somewhere, but I'm not.... it's according to how I feel, whether Imma have to change plans or not, so far I'm feelin' okay. So, at the end of the treatment I'll know.**

*(Man referred for transplant, Age 48, 2 years on dialysis)*

Travel limitations can make it difficult for dialysis patients to stay connected to family companions. If patients wish to travel for more than 2 days, they must arrange dialysis care in their destination city to avoid missing a day of treatment. One participant addressed this challenge this way:

**Before the dialysis, that's what we did, we traveled, you know, we would always be in Florida somewhere or, just goin' to see family, every opportunity we had, we would go, and just travel, and I miss that part, you know, being on dialysis, you**

**know. Even when we was to travel, like I said, I have to, even still do dialysis while I'm out of town. [Before dialysis], I would spend more quality time with my family and loved ones.**

*(Man not referred for transplant, Age 50, 3 years on dialysis)*

*Barriers to dialysis clinic relationships.* While dialysis center relationships were overwhelmingly portrayed as positive, they also have significant limitations. Almost all participants greatly valued the time spent with other dialysis patients while they are at the clinic, but seldom describe connecting with patients outside of the clinic. One patient talked about her lack of communication with people from the dialysis clinic after her treatments by saying,

**“You know, I see 'em here and then, I don't see 'em until I come back.”**

*(Woman not referred for transplant, Age 55, 6 years on dialysis)*

Receiving companionship from people at the dialysis center was also challenged by dialysis patients' frequent experiences with illness and death. Interview participants who had been on dialysis the longest described their challenges with companions from the clinic dying. Losing friends reduced the number of people participants could rely on for companionship and discouraged many from spending time and developing close connections with others. One participant said this:

**You know, I been on dialysis a long time, and I done see a lot of people die, you know, I have had a lot friends that....You know you befriend people on dialysis and I try not to get close to people no more like that, cuz when they pass, it bothers me.**

*(Woman not referred for transplant, Age 54, 6 years on dialysis)*

*Barriers to social relationships.* Many participants did not describe frequently spending time with friends or romantic partners during their time on dialysis when kidney transplant is

being considered or pursued. Most patients reported having a larger network of friends before they began dialysis. Common explanations for lost companionship corresponded with the ways that being on dialysis changes patients' every-day life. For example, changes in patients' daily activities, such as going to work, limits settings for spending time with existing friends or connecting with new ones. Dialysis lifestyle restrictions, including food and beverage restrictions, were another relationship barrier for some patients.

Maintaining romantic partnerships and developing new ones also proved challenging for many patients while on dialysis. Most dialysis patients (70%) reported being single. Many patients who were currently in a romantic relationship or had previously been in one while on dialysis described experiencing dialysis-related challenges in sustaining their relationships. For example, one woman described going through a recent breakup she attributed to her boyfriends' fears about her declining health and related neck surgery.

**I had a guy that had been with me for three years, but he kept tryin' to tell me that he, he didn't wanna be with me. Not that he didn't wanted to be with me... He didn't want me to pass on him, and when I got my neck cut open, like, he couldn't accept that, not cuz it's my neck, cuz of the pain and all I had to go through to do this, and he didn't wanna be... He scared, he real scared of the sickness.**

*(Woman referred for transplant, Age 38, 7 years on dialysis)*

Patients also described challenges for developing new romantic relationships while on dialysis. One man shared troubles with dating since being on dialysis this way:

**I usually, it's what I said, because I told you I had a friend...I got sick at her house and it's like, she didn't even visit me at the hospital or nothing... she called, but still,**

**you know what I mean, but when they see things like that, people like, you know, they think that you gonna need something. Like, need a ride or ask for help.**

*(Man referred for transplant, Age 51, 2 years on dialysis)*

### Social Support

This section presents common themes in dialysis patients' discussions about the social support they receive in the form of emotional, instrumental, informational and appraisal support for pursuing kidney transplant.

*Emotional Support.* Patient interview findings consistently revealed the importance of emotional support. Most patients shared experiencing feelings of sadness, depression, or anxiety related to their chronic kidney disease, being on dialysis, transplant surgery decision making, and fears of dying prematurely. Close loved ones, especially parents, siblings, partners, and children were key groups participants went to for emotional support when they were considering kidney transplant. Emotional support received from family members often took the form of "listening." Patients valued having someone to hear their enthusiasm, fears and concerns about kidney transplant and living on dialysis. Patients especially valued family members who extended emotional support, even when their opinions about kidney transplant did not align.

Patients and staff members from the dialysis clinic were also identified as key social network members who provided emotional support related to kidney transplant.

**Both [patients and staff at the dialysis clinic]. They listen to us when we goin' through family problems, they listen to us when we goin' through mental problems, cuz sometimes like now, we keepin 'it together, and sometimes they listen to us when you know, to be honest with you, I feel like [expletive] but I'm keepin' it together [laughs].**

*(Man referred for transplant, Age 48, 8 years on dialysis)*

Participants often valued the emotional support provided by other dialysis patients because of their unique ability to understand what it is like to be on dialysis, as an alternative to transplant.

**A couple people that's been on dialysis longer than me, and uh, showed me it's gonna be alright, and let me know I'm not in it, I'm not in it by myself, we all goin' through the same situation or the same, we in the same predicament.**

*(Man referred for transplant, Age 48, 8 years on dialysis)*

Interview findings revealed one challenge to dialysis patients obtaining ample emotional support being that many did not disclose to everyone in their networks they were on dialysis or considering transplant. This sometimes occurred because patients felt loved ones could not understand unless they had been on dialysis. Other times patients withheld information about problems they faced on dialysis to spare family members from worrying about them. Still others kept their dialysis status private to avoid people viewing them differently. One man said this about his emotional support system:

**I'm really kinda private about it. Some people ain't even know...But, I'm real proud about it. My wife does. She tells more about it to other people than I do. You know, "my husband's on dialysis--" I don't like for her to do that, but that's, that's the way she expresses herself, tellin', you know, but um, yeah, I'm very proud about it, because I'm like, this is somethin' that I'm really not comfortable with, but I know I have to do it, like I said, to survive. My circle in doin' that is very small.**

*(Man not referred for transplant, Age 50, 7 years on dialysis)*

*Instrumental Support.* Interview findings identified close family members and government-sponsored programs as the primary sources of instrumental support for the tangible

resources needed for kidney transplant. When patients were asked who they could go to for help if they needed it, they commonly identified routine tasks that required physical assistance but minimal cost as the easiest to access from their social network. Cost-free instrumental support was most often provided by close relatives or friends. For example, when asked who could help them cook a meal or clean up around their home, all but two participants identified network members who would be willing to do these things.

Accessing instrumental support in the form of transportation to doctor appointments required for the transplant evaluation process proved more difficult for many dialysis patients. Patients with the greatest confidence that they could access help with transportation from their networks qualified for free public transportation to medical visits or had close family members with cars. Many participants had trouble getting to evaluation appointments because they did not qualify for free public transportation but could not afford transportation fares for multiple trips to appointments. Several patients described missing transplant evaluation appointments because the transplant center was far from their homes and difficult to access using public transportation, especially for early morning appointment times.

Interview findings revealed that participants' social networks were more limited in providing instrumental support for financial needs that are important for transplant. For example, when asked who they could go to for \$100 if they needed help paying a medical expense, 22% (n=8) of patients felt they had no one to help them. Of the remaining 78% (n=29) who identified at least one family or friend who could give or lend them \$100, several suggested that this gesture would be financially challenging for their loved ones. Even greater concerns about cost were raised by participants when asked who they could go to if they had the opportunity to get a kidney transplant and needed help paying for related medical expenses or medication.

One participant replied:

**If [Medicare] don't cover it, it would be almost impossible for me to come up with the money to pay for my medicines.**

*(Man Not referred for transplant, Age 50, 3 years on dialysis)*

Another participant described finances as a chief barrier to transplant, saying this:

**I hope Medicare gonna pay for it. That's all, that's the only thing that's gonna stop me- I ain't got no money. I ain't got no family to go to do this or do that. I depend on the good Lord.**

*(Woman referred for transplant, Age 52, 8 years on dialysis)*

Another who completed the transplant evaluation, asked:

**Where am I gonna get all of this money from? That was my main thing, the financial, one was my main, as far as the transplant is concerned**

*(Man referred for transplant, age 51, 4 years on dialysis)*

*Informational Support.* Most participants identified transplant center and dialysis healthcare providers and staff members as their chief resource for informational support related to kidney transplant. When asked who they went to when they had questions related to kidney transplant, most patients described receiving information about transplant from physicians, techs and social workers at the dialysis clinic. All patients described knowing about kidney transplant before being interviewed.

**My doctor, I talk to my doctor, mostly, when I wanna ask a lot of questions... I'm gonna check with the doctor.**

*(Woman referred for transplant, Age 60, 5 years on dialysis)*

Most patients had not initiated the transplant evaluation process or visited a transplant center to learn more about their kidney transplant options. Individuals who completed an information session at their transplant center, typically had more detailed information about advantages and disadvantages of kidney transplant than those who didn't. However, having more information did not always encourage transplant. For example, most patients who did not complete the evaluation underestimated potential expenses associated with kidney transplant, such as Medicare only paying for 80% of medical expenses and losing Medicare coverage three years after the transplant surgery, and potential out-of-pocket costs of immunosuppressant medications that would be required post-transplant.

A secondary resource for transplant information came less formally through interpersonal relationships with other patients at the clinic. Participants described these conversations as casual exchanges by which patients could receive first-hand information from former patients who had received a kidney transplant and either came back to visit as a success story or had experienced a second kidney failure and were back on dialysis. As described above, conversations with previous transplant recipients varied widely in their content with some fostering positive social influence and social undermining regarding transplant.

Accurate informational support provided by healthcare professionals was sometimes undercut by misinformation provided by other sources due to medical distrust. Participants who described hearing negative transplant stories from other patients often trusted these sources for information about side effects and risks even when it conflicted with medical advice they received from physicians at the clinic. There was an underlying belief that the medical community were hiding information from them. Some were swayed against pursuing transplant because they were not confident they had adequate or reliable information about the benefits and



risks of the procedure. Medical distrust is evident in many patients' beliefs that the doctors are not telling them the truth or are withholding information.

**I talk to them about my diet, but they not givin' me the information that I want to hear. I asked them, "how do you get off of dialysis?" I asked them how do you cure kidney disease. And they said "you can't cure kidney disease." I talked to a person in here that's on dialysis, and they told me, I don't know if it's true, but if you go to foreign countries, they give you medicine that will cure your kidneys.**

*(Man referred for transplant, Age 51, 4 years on dialysis)*

*Appraisal.* Participants shared that physicians, family members, and other dialysis patients were key providers of appraisal support who helped with patients' self-evaluation and decision-making related to kidney transplant pursuit. Participants wanted to hear medical recommendations from their doctors.

**Family, doctors. I've been lucky to have some good doctors and nurses workin' over the years, so in that aspect, I've been real lucky, so, you know, they'll sit down and talk to you real. They don't do that acting or whatever they do.**

*(Man referred for transplant, Age 48, 2 years on dialysis)*

When family members were present, they assisted patients with sorting through information from the doctor to make the right decision. Still, there was a common sentiment among participants that the people they relied on outside of the clinic did not fully understand the dialysis experiences shaping their decision-making.

**You know, the problem is that they don't completely understand, because they don't, they haven't been through it.**

*(Woman not referred for transplant, Age 54, 26 years on dialysis)*

**Table 3.2: Common Themes from Georgia Dialysis Patients' (n=37) Interview Findings Related to Social Network Functions and Kidney Transplant Pursuit**

**Interest in Transplant**

- Most participants (81.6%) reported being interested in kidney transplant, but few (14%) were on the kidney transplant waitlisting list.
- Participants' expressed interests in kidney transplant changed over time and were negatively impacted by concerns of not qualifying for transplant.

**Social Network Functions**

**Social Influence**

Transplant recipients and family members were key resources for positive social influence regarding kidney transplant

- Successful transplant recipients encouraged interest and action steps toward transplant by providing visible examples of positive transplant outcomes.
- Family members who favored kidney transplant over ongoing dialysis care were often persuasive transplant supporters
- Young children or grandchildren inspired participants to pursue transplant as a means of living longer better-quality lives for their children.

**Social Undermining**

Few participants reported social undermining related to transplant pursuit.

- Social undermining may be mitigated by patients' commitments to staying positive to cope with life on dialysis.
- When reported, social undermining mostly came from former transplant recipients who shared negative stories about the downsides of transplant and personal adverse experiences with donor organ failure.

**Social Companionship**

Most companionship was received from small social network groups composed of close relatives and dialysis clinic patients and staff members.

- Bonds with family members were commonly identified as participants' most important and accessible social connections.
- Patient schedules and travel limitations posed challenges for maintaining relationships with close companions
- Maintaining companionship relationships with other dialysis patient was often challenging given patients declining health.

**Social Support**

- Emotional support was frequently obtained from close relatives in the form of listening.
- Instrumental support that provided non-monetary needs typically came from close relatives and friends, while support requiring financial assistance were primarily obtained from government agencies or non-profit organizations.
- Informational support related to kidney transplant was mostly obtained from dialysis center staff members and health care providers.
- Appraisal support useful for kidney transplant decision-making generally came from physicians, family member and other dialysis patients.

## V. Discussion

Social networks play important roles in shaping AA dialysis patients kidney transplant pursuits. In this qualitative study, findings from interviews completed with AA hemodialysis patients (1) described functions of patients' social networks (i.e. social influence, social undermining, social companionship, and social support) and (2) identified associations between these social network functions and kidney transplant pursuit. Patients generally described close-knit social networks within which they connected most frequently with relatives who lived locally and other dialysis patients. All participants faced challenges with maintaining relationships with network members while on dialysis, resulting in further declines in the size and diversity of their social circles over time.

### Social Influence

Findings about social influence suggest that dialysis patients may benefit from forming new, loose ties with successful transplant recipients. Qualitative data indicated that transplant recipients provoked increased interest and confidence in pursuing transplant by providing verbal encouragement and physical evidence of the benefits of transplant. These findings are supported by existing evidence that positive attitudes and social norms are associated with increased intentions to perform health behaviors (Ajzen, 1991) and that having a greater number of loose social ties supports transplant pursuit (Clark et al., 2008). Dialysis centers may be an ideal setting for connecting ESRD patients and successful transplant recipients because dialysis centers reach people earlier in their transplant decision-making process and are more accessible for individuals who face barriers to visiting the transplant center (Waterman et al., 2015).

### Social Undermining

Study findings did not yield frequent reports of social undermining directly influencing patients' thoughts or actions toward kidney transplant. Participants more commonly described ignoring negative comments as a means of safeguarding their health and well-being. Findings that did describe social undermining identified the chief source to be former transplant recipients who had previously experienced kidney graft failure and were receiving dialysis again at their clinic. Despite most participants' expressed commitments to ignoring social undermining about kidney transplant, they still routinely receive treatments near patients for whom kidney transplant eventually did not work. It is unclear the extent to which exposure to these experiences could indirectly shape their interest and pursuit of kidney transplant. It is possible that participants' commitments to staying positive lead to underestimating or underreporting how the negative stories they hear impact their attitudes and actions toward kidney transplant.

Future studies should seek to better understand dialysis patients' past experiences with graft-failure and how they may influence dialysis clinic environments. Increased knowledge about adverse transplant experiences could enhance transplant education by identifying modifiable risk-factors for organ rejection, providing more balanced information about the pros and cons of transplant, and addressing transplant mis-information when it is present. Learning more about graft-failure experiences may additionally help identify supports that former transplant recipients may need for readapting to life on dialysis.

### Social Companionship

Findings also revealed that most participants valued time spent with companions as critically important for pursuing kidney transplant. Participants most frequently relied on local family members and dialysis center friends as resources for companionship but described numerous challenges for sustaining these connections or building new relationships with others

while on dialysis. Evidence of declining social companionship while on dialysis is concerning given evidence that engaging with loved ones is linked to increased transplant pursuit (Rodrigue et al., 2008) and better mental health outcomes post-transplant (Mercado-Martinez et al., 2014). This study supports efforts to help ESRD patients maintain close ties with family members given evidence that relatives were the most reliable network connections for patients on the transplant pathway and suggests that innovative efforts to keep patients connected with companions who live long-distance may be especially helpful. Interventions aimed to foster relationships between dialysis patients should consider the fragility of these relationships. Dialysis patients' competing social and health challenges and heightened risks for illness and premature death may limit their capacity to be present for other patients who are pursuing kidney transplant.

### Social Support

Interview findings revealed everyday challenges experienced by dialysis patients that make emotional, instrumental, informational and appraisal social support critical for progressing through the transplant pathway. Findings conveyed that patients found it important to receive emotional support from their social network and valued close loved ones who listened to them. Feelings of depression, sadness, and anxiety were prevalent among patients, but few described reaching out for professional care beyond their immediate family and friends to obtain mental healthcare. These findings support clinic efforts that connect dialysis patients with professional mental healthcare services. A successful psychological intervention implemented by Rodrigue and colleagues, found that dialysis patients who received weekly quality of life therapy by professional therapists experienced improved quality of life and social intimacy compared to patients who received either structured support from dialysis social workers or did not receive supportive treatments (Rodrigue et al., 2011)

Results related to instrumental support showed that patients were often able to identify social network members who could help them with non-monetary resources important for kidney transplant pursuit, but seldom did they have network members that could adequately assist them with financial resources. This finding is concerning given that most participants had difficulties affording every-day expenses and experienced declines in socioeconomic status while on dialysis (United Network for Organ Sharing, 2011). Some funding methods recommended to patients for affording transplant, such as using crowd-funding websites or hosting fund-raising parties, are unrealistic given the demographics of patients' social circles. Most patients' social networks were small and socioeconomically homogenous and accordingly, did not have the capacity to provide the resources patients needed to pursue transplant and manage life after transplant.

At the individual level, intervention strategies that connect patients with patient navigators to assist with taking steps toward kidney transplant and policies that make financial coordinators available at transplant centers to assist with managing insurance processes may be especially useful in reducing barriers to transplant for patients with limited social support (Organ Procurement and Transplantation Network, 2018; Sullivan et al., 2012). However, even these approaches may be insufficient to address the larger cost barriers faced by many patients.

Introducing a national policy change to extend Medicare benefits to kidney transplant recipients beyond the current cut-off of 36 months post-transplant, would be critically important to meeting the needs of patients younger than 65 who are at the greatest risk of losing Medicare insurance benefits (Center for Medicare and Medicaid Services, 2014). Revising this policy to improve patients' eligibility for Medicare would play a vital role in making transplants more accessible to younger dialysis patients and ensuring medication compliance post-transplant,

especially among the growing population of adults who have low-incomes but do not qualify for Medicaid.

Study findings related to informational support revealed that patients receive most of their knowledge about kidney transplant from healthcare professionals at the dialysis clinic and that most had not completed the initial information session at the Transplant Center to begin the transplant evaluation process. Patients also described receiving first-hand, though often less reliable, information from transplant recipients. Standardized transplant education currently provided in Georgia transplant centers are linked to improvements in AA patient's knowledge (Patzer, Perryman, Pastan, et al., 2012). Interventions focused on informational support should eliminate the barriers to dialysis patients completing these transplant evaluation information sessions, such as inconvenient transplant center locations and hours. An alternative may be to offer this education session at patient's dialysis centers or to provide a web-based class that can be completed anywhere. Making the evaluation educational session available at dialysis clinics may benefit patients by providing more tailored information, which can better address patient concerns, transplant mis-information and medical distrust already spread between patients. Similarly, a web-based program can be adapted to patient needs and completed using the dialysis center wi-fi networks while patients are receiving treatments or at home.

Study findings related to appraisal support identified medical professionals at the dialysis clinic as the primary network members who helped participants make decisions about kidney transplant. This finding is complicated by the prevalence of kidney transplant myths and misinformation among patients. Medical distrust may help explain why patients trust incorrect information about transplant costs, side-effects and risks over information shared by their healthcare providers at the clinic when making decisions about kidney transplant. Links between

medical distrust and kidney transplant behavior have been established in previous studies (Lunsford et al., 2006). Given the extended exposure, established trust and close ties held in relationships between dialysis patients, interventions should seek to incorporate testimonies from transplant recipients to share pros and cons of kidney transplant surgery when promoting transplant.

### Interest in Kidney Transplant

Findings identified participants' interest in kidney transplant to be a dynamic construct that does not always align with transplant pursuit. Prior studies have commonly used single-item survey questions to assess interest. Conclusions drawn from such studies have narrowly suggested that lower than expected AA kidney transplant rates may be attributed to AA's disinterest in transplant (Ayanian, Cleary, Weissman, & Epstein, 1999). Our study diverges from prior studies by using comprehensive mixed methods to capture patient's interest in kidney transplant. Interview findings indicated that patients' expressed level of interest changed over time and are often colored by external factors including, social context, structural supports and positive and negative stories heard from others. These findings provide further evidence that patient interest in transplant is a complex, temporal construct that changes over time thus it may not be adequately captured by a single survey item. Data collection efforts may benefit from opportunities for reassessment.

### Social Networks and SES

Findings suggest that lower SES characteristics often limited social network functions related to transplant. Consideration should be given to the consistency with which themes related to SES emerged across social network interview discussions. For example, gaps in financial resources made it difficult for some patients to travel to the transplant center for informational



support or to visit family members for social companionship. Additionally, having fewer financial resources constrained network members' capacity to provide instrumental social support for transplant.

Findings suggesting that lower SES is associated with less supportive social networks are concerning because characteristics of patients' social networks are criteria for determining ESRD patients' transplant eligibility. At a national level, it is unknown how many patients are excluded from transplant based on social support nor are the criteria for doing so clearly defined. However, in a study conducted by Landin et al. (2019), transplant providers (n=551) estimated that, on average, 10% of dialysis patients evaluated for transplant were excluded from the transplant waiting list based on inadequate social support. Additionally, 67% of transplant providers felt that using social support as an eligibility criterion disproportionately impacted lower SES patients (K Ladin et al., 2019). Interview findings from this dissertation further suggest social support criteria may indirectly impact patients' decision-making and expressed interest in transplant based on their expectations about their eligibility for transplant.

National kidney allocation policies are guided by the challenge of organ scarcity, as the demand for kidney transplants far exceeds the supply of donor organs. Efforts to revise kidney allocation algorithms to reduce racial disparities in organ distribution have demonstrated early success (Melanson et al., 2017; Organ Procurement and Transplantation Network, 2014). Future transplant allocation policies should also consider how excluding patients from the transplant waiting list for not having enough social support, institutionalizes racial and economic disparities in access to transplant.

Projects committed to promoting equity and access to renal therapy in the U.S. should aim to strengthen social network functions for dialysis patients by finding practical ways to connect patients to local resources such as accurate information and reliable transportation that are not easily accessible in some patients' immediate social circles.

### Limitations

This project is not without limitations. This study only enrolled participants from three hospital-owned dialysis clinics in Atlanta, Georgia. Thus, findings may not be reflective of dialysis patients' experiences at other types of dialysis clinics, such as for-profit clinics or clinics located in different geographic locations. Additionally, this study relies primarily on ESRD patients' first-person accounts to answer its research questions. A weakness of self-reported data sources is their susceptibility to social desirability and recall bias. However, this project considers the risks of response bias to be far outweighed by the benefits of learning from ESRD patients' primary accounts of their various experiences on dialysis. It is unlikely that more objective collection methods could better capture the depth of these findings. To maximize the credibility of the data, we triangulated findings reported by ESRD patients on important clinical outcomes of interest (including reports of whether patients expressed interest in, received a referral for, or were waitlisted for transplant) with medical record data from respective dialysis clinics.

### Strengths

Despite the limitations of this study design, a substantial strength is this project's emphasis on identifying key interpersonal-level socioenvironmental characteristics associated with disparities in pursuit of transplant. This work is innovative and important for the ways in which it highlights the meaningful role of social networks in shaping transplant pursuit. This

paper identifies modifiable aspects of patients' social network connections to reveal opportunities for supportive interventions. Additionally, this study's mixed methods approach yielded rich explanatory descriptions about the relationship between Social Network functions and pursuit of transplant. Findings generated from this study enhance the public health literature by elucidating social determinants associated with kidney transplant pursuit and by recommending insightful strategies for improving patients' access to kidney transplant.

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## Chapter Four - Socioeconomic Decline and Kidney Transplant Pursuit

A Qualitative study examining African American end-stage renal disease patients' experiences with socioeconomic decline while on dialysis and its associations with pursuit of kidney transplant

### I. Introduction

End stage renal disease is a chronic condition characterized by irreversible kidney failure. Individuals with ESRD must rely on either dialysis or a kidney transplant to survive. Kidney transplant is the treatment of choice for many people experiencing ESRD given evidence that individuals who receive transplants have better health outcomes, live longer, and experience higher quality of life, compared to people who remain on dialysis (Southeastern Kidney Council, 2014; Tonelli et al., 2011). Unfortunately, in the U.S., few dialysis patients receive kidney transplants, largely because of scarce donor organ supplies (United States Renal Data System, 2018). In 2013, the active transplant waiting list was 2.7 times greater than the quantity of donor kidneys (United States Renal Data System, 2018).

The standard pathway for pursuing a kidney transplant involves a set of progressive steps that begin with being diagnosed with ESRD (Figure 1.1). Ideally, patients would obtain adequate transplant education, express interest in receiving a transplant, be referred to a transplant center by a kidney specialist and successfully complete a transplant evaluation. In many transplant centers, the evaluation is an extensive multidisciplinary process that provides transplant education and assesses whether patients meet minimum health, social support, home and financial viability criteria (Organ Procurement and Transplantation Network, 2014). Eligible patients who have a compatible living organ donor will proceed to kidney transplant. Otherwise, patients are added to a national waitlist registry until they are matched with a suitable organ from

a deceased donor through the Organ Procurement and Transplantation Network's (OPTN) Kidney Allocation system (Organ Procurement and Transplantation Network, 2014)

Various economic resources are required for ESRD patients to successfully progress through the transplant pathway and undergo a successful transplant. Medical expenses associated with transplant include costs for insurance deductibles and co-payments, transplant evaluation medical procedures, kidney transplant surgery and follow-up physician appointments. Additionally, after receiving a kidney transplant, patients are required to take immunosuppressive medicines, which can cost more than \$2,500 per month without insurance, for the rest of their lives to prevent their bodies from rejecting the new kidney (Bently, 2014; United Network for Organ Sharing, 2011). Medicare, a federally managed public health program, provides health insurance for all ESRD patients and covers the vast majority of these medical costs (Center for Medicare and Medicaid Services, 2014). However, transplant recipients are financially responsible for 20% of Medicare-approved kidney transplant surgery costs for doctor services and for various portions of transplant clinic charges (United Network for Organ Sharing, 2011). Additionally, 36 months after kidney transplant surgery, recipients who are younger than 65 may become ineligible for Medicare coverage (Center for Medicare and Medicaid Services, 2014). Medical expenses not covered by Medicare are commonly covered by Medicaid (a public insurance option for the extremely poor), by private insurance, or from out-of-pocket spending. Transplant-related costs may be especially challenging for individuals who cannot afford private health insurance but have incomes too high to qualify for Medicaid (United Network for Organ Sharing, 2011).

Economic resources are also required to manage non-medical transplant expenses, often not covered by public or private health insurance. These costs include transportation to and from

the transplant center, childcare costs, lost wages, and lodging if the transplant center is not close to the patient's home (United Network for Organ Sharing, 2011). Economic resources are a barrier to transplant for many ESRD patients because individuals who cannot provide evidence of their ability to afford these costs generally do not get transplanted (United Network for Organ Sharing, 2011).

In the U.S., SES is a well-established determinant of access to kidney transplant (Axelrod et al., 2010; Ozminkowski et al., 1998; Patzer & McClellan, 2012). Americans with lower SES have a greater risk of developing ESRD (Ward, 2008) but are still less likely to receive a kidney transplant compared to people with higher SES (Akistanbullu & Yilmaz Ulusoy, 2017). For example, patients who are unemployed, earn lower incomes or live in poorer neighborhoods experience reduced access to transplant, compared to patient with higher SES characteristics (Keith et al., 2008; Kurella-Tamura et al., 2014; Ozminkowski et al., 1998; Patzer et al., 2009; Petersen et al., 2008).

African American ESRD patients experience disproportionately low kidney transplant rates that are 40% less than white American ESRD patients' rates and may be partly attributed to socioeconomic inequities (Patzer & Pastan, 2014; United States Renal Data System, 2018; Volkova et al., 2008). On average, AA dialysis patients are twice as likely to be unemployed and have lower incomes, compared to white Americans (Tzvetanov et al., 2014). Additionally, poor AAs are at greater risk of living in poor communities, compared to poor white Americans (Jargowsky, 2015).

The relationship between individual SES and access to kidney transplant may be especially pronounced for AAs, given evidence that poor AAs are 67% less likely to be placed on the donor waiting list than poor whites (Patzer et al., 2009). Additionally, a study conducted

by Patzer and colleagues found that as neighborhood poverty increased, gaps between AA and white patients' transplant waitlisting rates widened, with AAs residing in the poorest neighborhoods being 57% less likely to be waitlisted than whites living in the poorest neighborhoods (Patzer et al., 2009)

While higher SES is linked to improved access to kidney transplant, especially for AA ESRD patients; approximately 45% of adult patients lose their fulltime employment status after initiating dialysis (United States Renal Data System, 2018). Findings from previous studies provide additional evidence of dialysis patients' experiences with socioeconomic decline, but have primarily applied quantitative methods to identify employment, income and insurance status as a limited set of indicators of SES changes (Nakayama et al., 2015; Rongey et al., 2005; Tzvetanov et al., 2014). No studies to our knowledge have examined whether AA patients' SES before initiating dialysis colors their encounters with socioeconomic decline while on dialysis. More research is needed to understand AA dialysis patients' encounters with socioeconomic declines and how these changes potentially inform transplant pursuit. This paper describes a qualitative study designed to assess how patient experiences with SES declines while on dialysis shape pursuit of kidney transplant, among AA hemodialysis patients in Georgia, in order to inform future interventions that promote equity in access to kidney transplant. Study findings are used to answer the following four research questions:

1. What are AA ESRD patients' experiences with decline in SES while undergoing hemodialysis?
2. What are AA ESRD patients' experiences with loss of financial resources important for transplant while undergoing hemodialysis?

3. In what ways does SES prior to dialysis help explain socioeconomic decline experienced by AA patients while undergoing hemodialysis?
4. In what ways are AA patients' experiences with socioeconomic decline while undergoing hemodialysis associated with pursuit of kidney transplant?

## II. Methods

We conducted semi-structured in-depth interviews coupled with electronic questionnaires in-person with AA hemodialysis patients (n=37). Qualitative exploratory methods were applied to capture descriptive details about patients' dialysis experiences, socioeconomic changes on dialysis and perspectives on pursuing a kidney transplant through patient interviews (Hsieh & Shannon, 2005; Salazar et al., 2011).

### Participant Selection and Setting

Participants were eligible for this study if they were current hemodialysis patients between 21 and 60 years old who had been on dialysis for at least six months and self-identified as Black or AA. Participants were recruited at one of three non-profit, hospital-owned dialysis clinics located in metropolitan Atlanta, Georgia. Participants were recruited using study flyers distributed in dialysis clinic patient areas by clinic social workers and the principal investigator. The principal investigator screened and enrolled participants using quota sampling to ensure that the study sample varied by dialysis clinic, referral status and gender. Across the three dialysis clinics, 19 women (10 referred for transplant, 9 not referred for transplant) and 18 men (9 referred for transplant, 9 not referred for transplant) were enrolled for a total of 37 study participants. Emory's Institutional Review Board (IRB) granted approval for this study (IRB00096498).

### Data Collection

Thirty-seven qualitative interviews were completed in-person during patients' dialysis treatments between June and August 2017. Written informed consent was obtained from all study participants prior to participation. Supplemental patient data were collected at dialysis clinics using a brief electronic patient survey and by reviewing each participant's medical chart to confirm clinical information related to dialysis and pursuit of transplant.

### Measures

The study team developed a structured, qualitative interview guide that contained simple, open-ended questions and prompts for patients to describe their: 1) health progression from kidney disease to ESRD, 2) interest in and pursuit of kidney transplant, 3) perceived SES one year prior to beginning dialysis, 4) current perceived SES, 5) access to socioeconomic resources important to transplant one year prior to beginning dialysis, 6) current access to socioeconomic resources important to transplant, 7) perspectives on how changes in SES and their available resources relate to transplant interest and pursuit. Questions related to perceived SES before and after beginning dialysis incorporated the validated MacArthur Scale of Subjective Social Status, whereby participants were shown a printed image of a ladder with 10 rungs and asked to rank their social standing on a scale from one to ten. The first and tenth rung of this ladder-based scale indicated people who were the worst and best off, respectively, based on their money, education and employment situations (Adler & Stewart, 2007). Questions related to "socioeconomic resources" included prompts about participants' ability to access transportation, housing, groceries, childcare, health insurance and other basic socioeconomic resources identified by dialysis clinic staff and the United Network of Organ sharing as important for transplant (United Network for Organ Sharing, 2011). All interviews were audio-recorded in entirety using a digital recorder and lasted an average of 62 minutes (SD=19.8) minutes.

Following the interview, additional patient data were collected using a brief electronic survey and a medical abstraction form. The electronic survey collected information on patient demographics, kidney transplant pursuit, socioeconomic resources before dialysis and current socioeconomic resources. Demographic questions asked participants to share their age, gender, marital status, and race/ethnicity. Survey items related to kidney transplant pursuit included two questions. First, participants answered the question, “How interested are you in pursuing a kidney transplant?” Response options were “Very interested”, “Somewhat interested”, “Neutral”, “Not very interested”, or “Not at all interested”. Second, participants answered the question, “Would you undergo kidney transplant if you are given a chance when the time comes?” by responding “Yes” or “No”. Questions related to socioeconomic resources before dialysis and currently asked patients about their income range, employment status, employment type, educational attainment, medical expenses and non-medical expenses one-year before dialysis and at the time of the interview.

The medical abstraction form collected data on patients’ demographics, ESRD progression and transplant wait-listing status. ESRD progression items included questions about patients’ initial dialysis start date, transplant center referral status, and transplant waitlisting status. Study participants were given a \$30 cash incentive after completing the interview and survey.

### III. Data Analysis

Audio recordings of interview sessions were transcribed verbatim by the principal investigator and an Emory University graduate assistant and verified by study team members to ensure accuracy. A preliminary codebook manual was developed by using the nested themes from the interview guide to name key codes in interview transcripts. To strengthen validity, a



consensus meeting was held during which study team members revised the preliminary codebook based on their working-knowledge of the interview data, to ensure that each code had the capacity to accurately capture key themes. Using the qualitative data management software – Atlas.ti, a total of 73 codes, nested within 11 code families were included in the final coding manual.

The principal investigator coded all transcripts using the revised codebook. To strengthen study reliability, the principal investigator discussed sample quotations for each code with a study team member after coding the first transcript to achieve consensus on how codes would be applied. Exploratory qualitative methods were applied to analyze interview data using a deductive process based on the interview guide domains (Patton, 2002). Analyses also confirmed and expanded upon theorized relationships between socioeconomic decline and kidney transplant pursuit. Study findings emerged from persistent themes and prevalent data trends identified in the coded qualitative transcripts. (Hsieh & Shannon, 2005; Patton, 2002; Salazar et al., 2011).

#### IV. Results

Interviewed participants (N=37) had a mean age of 49 years (SD= 8). Most participants completed at least high school or a GED (86%), while 16% additionally completed college or graduate degrees. Patients were mostly single (70%) and unemployed (84%) with incomes less than \$10,000 per year (51%). Almost all patients received Medicare (97%), with many also receiving Medicaid (70%) (Table 4.1).

Results gathered from the MacArthur Scale of Subjective Social Status revealed current mean SES scores of 4.4 compared to mean SES scores of 5.4 one year before dialysis (where 0=lowest SES and 10=highest SES) demonstrating a 13% decline in average SES. Most participants (n=22, 59%) described experiencing declines in their SES while on dialysis, with

fewer patients describing no change (n=6, 16%) or modest increases in their SES (n=9, 24%) (Table 4.1).

<b>Table 4.1: Characteristics of Patients (N=37) Receiving Care from Three Georgia Dialysis Clinics, Reported by Self-Reported Changes in SES While on Dialysis</b>			
<b>Participant Characteristics</b>	<b>All Patients</b>	<b>SES Declined</b>	<b>SES Maintained or Increased</b>
	<b>n=37</b>	<b>n=22</b>	<b>n=15</b>
	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>
<b>Mean Perceived SES (SD)</b>			
<b>1 Year Pre-dialysis</b>	5.38 (2.24)	6.27 (2.33)	4.07 (1.28)
<b>Current</b>	4.41 (1.87)	3.98 (1.84)	5.03 (1.78)
<b>Mean change in Perceived SES (SD)</b>			
<b>Difference (Current - Pre-dialysis)</b>	-0.97 (2.06)	-2.29 (1.42)	+0.97 (1.08)
<b>Ratio (Current: Pre-dialysis)</b>	0.87 (0.38)	0.62 (0.21)	1.23 (0.25)
<b>Mean Age in years (SD)</b>	49.13 (8.07)	51.32 (6.03)	45.93 (9.71)
<b>Mean years on dialysis (SD)</b>	6.68 (6.27)	6.14 (5.63)	7.47 (7.23)
<b>Sex</b>			
<b>Male</b>	18 (49%)	11 (50%)	7 (47%)
<b>Female</b>	19 (51%)	11 (50%)	8 (53%)
<b>Education completed</b>			
<b>Less than High school</b>	5 (14%)	3 (14%)	2 (13%)
<b>High school or GED</b>	17 (46%)	6 (27%)	11 (73%)
<b>Some College</b>	9 (24%)	7 (32%)	2 (13%)
<b>Bachelor's Degree</b>	5 (13%)	5 (23%)	0
<b>Graduate or Professional School</b>	1 (3%)	1 (5%)	0
<b>Marital Status</b>			
<b>Married or Domestic Partner</b>	11 (30%)	4 (18%)	7 (47%)
<b>Divorced or Separated</b>	13 (35%)	11 (51%)	2 (13%)
<b>Never Married</b>	13 (35%)	7 (32%)	6 (40%)
<b>Current Employment Status</b>			
<b>Unemployed</b>	31 (84%)	20 (90%)	11 (73%)
<b>Working part time</b>	4 (11%)	1 (5%)	3 (20%)
<b>Working full-time</b>	2 (5%)	1 (5%)	1 (7%)
<b>Current Income</b>			
<b>Less than 10,000</b>	18 (50%)	10 (45%)	8 (57%)
<b>10,000 to 25,000</b>	10 (28%)	6 (27%)	4 (29%)
<b>25,000 to 50,000</b>	4 (11%)	4 (18%)	0
<b>More than 50,000</b>	1 (3%)	0	1 (7%)
<b>Prefer Not to Say</b>	4 (11%)	2 (9%)	2 (14%)
<b>Current Health Insurance</b>			
<b>Medicare</b>	36 (97%)	21 (95%)	15 (100%)
<b>Medicare Only</b>	2 (5%)	2 (9%)	0
<b>Medicare + Private Insurance</b>	10 (22%)	14 (64%)	10 (67%)
<b>Medicare + Medicaid</b>	26 (70%)	5 (23%)	5 (33%)
<b>Not Insured</b>	1 (3%)	1 (5%)	0
<b>Home owner</b>	3 (8%)	3 (14%)	0
<b>Afford \$100 out-of-pocket medical expense</b>	11 (30%)	5 (24%)	6 (40%)

Participants' survey responses regarding interest in receiving a kidney transplant were overwhelmingly positive. When asked if they were willing to get a transplant when the time comes in the post-interview survey, 81% of participants replied "yes". Similarly, participants' mean interest score was 4.11, when asked how interested they were in getting a transplant on a scale from one to five (where 1=not at all interested, 5=very interested). However, only 16% of participants were waitlisted for transplant. Interview findings further revealed that participants' decisions to express interest in or pursue a kidney transplant were often contingent on other external factors, such as whether they believed they could afford transplant or would meet the eligibility requirements for a transplant.

This section presents key themes that emerged from the qualitative patient interviews to describe experiences with socioeconomic declines while on dialysis related to kidney transplant pursuit. Descriptions of these themes are organized by this study's four research questions. A summary of themes is outlined in

**Table 4.2: Common Themes from Georgia Dialysis Patients' (N=37) Interview Findings Related to Socioeconomic Declines While on Dialysis and Kidney Transplant Pursuit**

**Table 4.2: Common Themes from Georgia Dialysis Patients' (N=37) Interview Findings Related to Socioeconomic Declines While on Dialysis and Kidney Transplant Pursuit**

**RQ1: Experiences with Declines in SES**

- Most participants (60%) experienced declines in their SES, characterized by:
  - Lost employment due to dialysis treatment schedules, illness, and disease stigma
  - Reduced earned income due to lost employment
  - Decreased financial stability characterized by reduced assets and increased debt

**RQ2: Experiences with Declines in Financial Resources Important for Transplant**

- SES declines were often coupled with lost resources that may be vital for pursuing transplant, including the ability to afford:
  - Affordable transportation
  - Housing stability
  - Private medical insurance

**RQ3: Links between Pre-dialysis SES and SES Declines on Dialysis**

- Among patients who reported high SES before beginning dialysis (n=15)
  - Most (93%) experienced declines in SES
- Among patients who reported low SES while on dialysis (n=22),
  - Most (64%) reported having low or moderate SES 1 year before dialysis
  - Improved SES was attributed to increased income and Medicare health insurance

**RQ4: Links between Declining SES and Transplant Pursuit**

- Lost Resources strained opportunities to perform transplant related behaviors
- Declining financial resources contributed to concerns and uncertainty about being unable to afford out-of-pocket kidney transplant surgery expenses

Research Question 1: Experiences with Declines in SES

Twenty-two (59%) of the 37 study participants reported declines in SES while on dialysis. Discussions about SES declines primarily described lost employment and income and reduced financial stability. Regarding employment, 21 of the 22 study participants who reported SES declines were unemployed, despite many participants describing working before beginning dialysis. Most participants wanted to return to work but faced numerous barriers to gaining employment including scheduling conflicts with dialysis treatment times, physical limitations, and concerns that employers would not want to hire ESRD patients because of their disease status. Given the time constraints of receiving hemodialysis for several hours, three days a week, some patients who were interested in part or full-time employment felt they did not have the

schedule flexibility or availability during traditional daytime business hours that many jobs require.

Experiences with physical limitations related to dialysis and other common health complications, such as diabetes or high blood pressure, were also a concern for employment. One participant described how feeling sick made it difficult to participate in normal activities, including working.

**I prefer to work, but I have to get up at 3 in the morning and be here by 5:45, it impacts it because sometimes I wanna sleep, and it takes so much of my time since I live alone... my whole schedule has changed...When I come here, get on dialysis, some days I feel good...but somedays I just have to leave here and go straight home. It tears my body down. Somedays it's good days, somedays I feel drained.**

*(Man not referred for transplant, Age 53, 11 years on dialysis)*

Other common examples of physical limitations include medical restrictions on physical activities, such as recommended heavy lifting and descriptions of losing physical strength while on dialysis. These physical challenges to employment were frequent concerns because many study participants had service oriented or labor-intense jobs in areas such as construction work, food services, and inventory stocking. Unemployed participants frequently described having jobs that would be physically difficult to perform while on dialysis.

Some participants described being interested and able to gain employment on dialysis but were concerned that potential employers would not consider them because of stigma associated with ESRD and assumptions that dialysis patients will not be reliable workers. Several participants described actions such hiding their scars from their dialysis access sites with

bandages or lying about reasons they could not lift heavy objects to prevent current or potential employers from knowing about their kidney disease.

Lost employment resulted in steep decreases in income for participants who described sudden shifts from earning employment income one-year before dialysis to receiving modest monthly disability checks while on dialysis. Forty-five percent of participants who experienced a decline in SES had individual incomes less than \$10,000 per year while on dialysis. One woman shared this about her current unemployment status and its impact on her financial situation:

**Well [before dialysis] I was able to make more money, cuz I was able to work. But now...I can't work the hours that I need to make me feel financially situated.**

*(Woman not referred for transplant, Age 54, 24 years on dialysis)*

Participants who experienced socioeconomic declines described challenges with financial stability, often characterized by reduced assets and increased debt. One man described her concerns with her financial situation this way:

**Yeah, cuz I ain't got the money I used to have, and I don't work, so, I can't live that life like that no more. All I got is bills and I ain't got no money, all I got is a bunch of bills.**

*(Man not referred for transplant, Age 54, 13 years on dialysis)*

Many participants described financial challenges growing more difficult as their time on dialysis progressed.

**Cuz less money and it's gettin' harder too. Like I said, this is your last go around [in life] and they leave you out there, you know.**

*(Man not referred for transplant, Age 54, 6 years on dialysis)*



Experiences with socioeconomic decline were often coupled with financially-risky coping behaviors such as depleting savings accounts, allowing unpaid bills to go to collections agencies, pre-maturely withdrawing money from retirement investments and selling or losing property such as cars or homes.

### Research Question 2: Experiences with Declines in Material Resources

Interview discussions about declines in SES while on dialysis often revealed concerns with decreases in material resources that are important for patients pursuing kidney transplant, such as reliable transportation, stable housing and private medical insurance coverage. Lost material resources were not independent of changes in employment and income; rather, patients described no longer being able to afford these resources because of their reduced employment and income. When asked about his experiences with declines in SES, one participant also described lost material resources.

**I lost everything, I had a crib, a car, everything. Everything. I had all I needed to survive and be responsible for what I need to do, and I lost everything on account of me gettin' myself sick. Which is only material stuff but shit I work hard for that material thing... so by losing that...it really was a devastation, cuz I had to move back to my mom's crib, and I didn't wanna do that.**

*(Man referred for transplant, Age 43, 2 years on dialysis)*

Patients who experienced SES declines frequently reported trouble affording transportation to essential locations, including the transplant center, doctor appointments, pharmacies and grocery stores. Some participants who owned cars experienced transportation challenges if they could no longer afford gas or maintenance to operate their cars. Most patients relied on public transportation and shared that out-of-pocket travel fares were difficult to

manage. Concerns about transportation costs persisted even among participants who received government subsidies for public transportation because this assistance often only reduced fare costs and were typically limited to routine trips to the dialysis clinic.

Housing stability was another common concern vocalized by study participants. Several patients described having to downsize to less expensive rental units or selling or losing their homes because they could not manage housing costs. Many patients described moving in with family members because of financial challenges. Housing was especially challenging for participants who did not qualify for government subsidized housing but could not afford to pay market-value rent with their incomes.

Some participants also described experiences with losing private health insurance coverage. Many participants (36%) who experienced SES declines did not receive Medicaid and had some out-of-pocket expenses associated with medicine costs or physician visits (Table 4.1). One participant who had only Medicare described financial difficulties he experienced with managing prescription costs.

**[My financial situation is] Bad because my medicine I have to pay for it sometimes. Some of it is so high. [Medicare] covers some of it. But my Insulin and stuff I have to pay for.**

*(Man not referred for transplant, Age 54, 1 year on dialysis)*

Gaps in health insurance left some with mounting medical bills they could not afford.

**I had some medical bills like, if I had to go to the emergency room or whatever, the bill just didn't get paid.**

*(Woman referred for transplant, Age 45, 7 years on dialysis)*

### Research Question 3: Links between Pre-Dialysis SES and SES Changes on Dialysis

Interview discussions revealed links between participants' SES before dialysis and their experiences with socioeconomic decline and loss of resources while on dialysis. Participants who reported high perceived SES before dialysis were most vulnerable to losing employment, income and material resources while on dialysis. Of the 37 study participants, 40% (n=15) perceived themselves to have had high SES one year before beginning dialysis. Of the participants with high perceived SES the year before dialysis, all but one (93%) reported declines in SES after they began treatments (Table 4.3). Participants who described having high SES before beginning dialysis were often employed and making salaries that were higher than their current disability checks. Before beginning dialysis, most (80%) were confident that they made enough resources to afford their basic needs.

<b>Table 4.3: Associations between SES before dialysis and SES decline on dialysis</b>		
<b>Changes in SES</b>	<b>Low SES*, Scores 0 to 5 (n=22)</b>	<b>High SES*, Scores 6 to 10 (n=15)</b>
<b>SES Decrease</b>	8	14
<b>SES Maintain/Increase</b>	14	1
<b>*Low and High SES were captured based on results gathered from the ladder-based ranking system used to capture each participant's perceived SES scores</b>		

Several themes were prevalent in participants' descriptions about the characteristics of their financial situation before dialysis that could have made them more susceptible to SES declines. For example, participants commonly worked jobs that were not feasible to work while on dialysis. Few participants described having employee benefits such as disability insurance or disability leave that would have provided added financial support while they transitioned to dialysis. Patients often described their social networks as having limited capacities for providing

financial support if they needed it. Few patients described having emergency savings before beginning dialysis that could have lasted them more than two months.

Among the 22 study participants (59%) who reported having low SES before dialysis, most described their SES as either staying the same (n=5, 23%) or increasing (n=9, 41%) while they were on dialysis (Table 4.3). Study participants commonly attributed their improved SES to increases in income from disability payments and improved access to health insurance through Medicare enrollment, both benefits for which most patients are granted eligibility by their ESRD diagnosis.

Study participants who reported low SES before beginning dialysis often described facing significant financial and health-related hardships in the years preceding kidney failure and were commonly unemployed or uninsured before beginning dialysis. When asked about his financial situation the year before beginning dialysis, one participant shared this.

**At the time they said that I couldn't work because I couldn't lift nothin' up cuz my heart was weak. I got sick. And I wanted to get unemployment, but they said I quit. But, I ain't quit. I got sick [because of congestive heart failure], and so I had to depend on my, my mother-in-law for financial support...Sometimes I got a little stressed.... Cuz I, I wasn't workin'. And I can't provide for my family**

*(Man referred for transplant, Age 44, 6 months on dialysis)*

When asked what she was proud of when it came to her financial situation the year before she began dialysis, one woman had a hard time identifying anything positive and instead responded:

**I was broke. It was all bad. There was nothing good about it.**

*(Woman not referred for transplant, Age 55, 3 years on dialysis)*

For many people in this subset of dialysis patients who had low SES before dialysis, being diagnosed with ESRD provided stable income and medical benefits that assisted them in improving their already strained socioeconomic situations. Participants valued the benefits that they gained access to after beginning dialysis because they helped them to afford basic needs. When asked why he felt his social standing had improved while on dialysis, one person shared:

**I can do what I want to now. But, when I didn't have no money, I had to do what people said I had to do to survive. But now I don't have to depend on nobody.**

*(Man referred for transplant, Age 44, 6 months on dialysis)*

Notably, among the group study participants who reported maintaining or increasing their SES after beginning dialysis, most still had relatively low current incomes. Fifty-seven percent of participants who maintained or increased their SES receive less than \$10,000 annually while on dialysis. One man spoke positively about the disability income he received while on dialysis while also admitting challenges in using it to meet his family's needs.

**Altogether, between me and my wife, our income is about \$1100. That's almost impossible...(laughs) for anybody to live off of.**

*(Man not referred for transplant, Age 50, 2 years)*

#### Research Question 4: Declining SES and the Pursuit of Transplant

Interview findings revealed reoccurring themes regarding ways declines in socioeconomic standing and fewer material resources create barriers for transplant pursuit to include concerns about affording costs associated with navigating the pathway to receipt of a transplant, transplant surgery, and long-term healthcare post-transplant.

Participants who experienced SES declines commonly identified ways lost resources made it more difficult to pursue kidney transplant. For example, reduced access to reliable

transportation was frequently described as a barrier to going to doctor appointments and transplant center visits required for the transplant evaluation process. Unfortunately, most participants did not live or receive dialysis treatments near the clinics that housed these services. For individuals who could no longer drive or afford out-of-pocket costs for public transportation to places besides the dialysis clinic; arranging transportation to complete the transplant evaluation was a significant hurdle in navigating the transplant pathway.

Declining SES and lost material resources also made it more difficult for dialysis patients to afford kidney transplant surgery expenses that are not covered by Medicare. Patients expressed uncertainty regarding how much surgery could cost and how much they would be personally responsible for paying. Several participants expressed being afraid that they could not afford out-of-pocket costs given their current financial hardships. When asked about her thoughts about kidney transplant costs, one woman shared this:

**I think they say [a transplant costs] \$10,000, or I think Medicaid will pay for it, I don't know, like, Medicaid will pay for certain parts of it, but not the other part? I'm not financing it.**

*(Female referred for transplant, Age 38, 5 years on dialysis)*

Another participant shared this:

**You know, my brother was tellin' me at first, they said that he would need \$7,000 dollars, and I'm like \$7,000? And I'm like, man! Nobody got that just layin' around!**

*(Female not referred for transplant, Age 49, 3 years on dialysis)*

Some participants described the medical costs associated with transplant surgery were a major barrier.

**I got all that information but... It was just too overwhelming for me at that time, I was fresh on dialysis and I'm like, ugh, where am I gonna get all of this money from? That was my main thing, the financial [part], as far as the transplant is concerned.**

*(Male referred for transplant, Age 51, 2 years on dialysis)*

Dialysis patients were frequently unclear about how they would afford long-term healthcare costs post-transplant. Because study participants were all ages 60 years or younger, they did not meet the standard 65-year age criteria for Medicare and could lose Medicare insurance coverage three years post-transplant.

**I think they said you know, Medicare only pays for the medications for so long, and then you have to be able to pay for 'em yourself, so that kinda like worried me.**

*(Female not referred for transplant, Age 49, 3 years on dialysis)*

Losing medical insurance coverage was concerning for many participants who frequently had other chronic health conditions, such as diabetes or high blood pressure associated with healthcare costs. Additionally, all transplant recipients are required to take ongoing immunosuppressant medications post-transplant that are very expensive post-transplant. Managing future post-transplant health care costs may be especially challenging for individuals who will not qualify for Medicaid post-transplant and for those who have trouble finding jobs that provide insurance benefits.

Participants' concerns about having the money and resources required to undergo kidney transplant surgery, navigate the transplant pathway and afford immunosuppressant medication post-transplant may help explain the success in accessing kidney transplant in two ways. For some patients, fears about cost often shaped their confidence in their ability to get a transplant,

interest in transplant, or willingness to communicate interest in transplant to their healthcare provider. For many patients, fears about financially affording costs associated with kidney transplant may accurately reflect their ineligibility for transplant if they cannot verify their financial viability to manage ongoing medical expenses.

## V. Discussion

Substantial resources are required for dialysis patients to successfully pursue kidney transplant. In this qualitative study, interviews completed with AA hemodialysis patients assessed patient experiences with declines in SES while on dialysis and how these changes shape pursuit of kidney transplant, in order to inform future interventions that promote equity in access to kidney transplant. Interview findings responded to this study's research questions by describing (1) experiences with SES declines and (2) lost material resources while on dialysis, (3) links between pre-dialysis SES and SES declines on dialysis, and (4) links between SES declines on dialysis and transplant pursuit. African American dialysis patients described various experiences with SES declines and lost material resources while on dialysis, that were guided by their SES before dialysis and helped explain their pursuit of kidney transplant.

### Research Question 1: Experiences with declines in SES while on Dialysis

Study findings regarding reduced employment, income, and financial stability while on dialysis are consistent with previous studies that also link dialysis initiation with declines in SES (Murray, Dobbels, Lonsdale, & Harden, 2014; United States Renal Data System, 2018). Evidence that most participants wanted to work but identified dialysis as a barrier to employment is well supported by previous research findings (Kutner & Zhang, 2017; Murray et al., 2014). These study findings undermine false narratives that stereotype disabled patients as using their condition to unfairly access benefits (University of Washington, 2016). Low employment among



participants is concerning given evidence that people who are employed on dialysis are more likely to receive a kidney transplant (Tzvetanov et al., 2014). Furthermore, compared to individuals who are employed, individuals who are unemployed at the time of transplant are less likely to work after transplant and subsequently have lower patient and donor organ survival rates (Petersen et al., 2008; Tzvetanov et al., 2014). Low employment is also concerning because patients associated not working to reduced income and financial instability, which made it difficult for many patients to meet their basic needs.

#### Research Question 2: Lost Material Resources while on Dialysis

Results describing socioeconomic losses in reliable transportation, stable housing and private medical insurance while on dialysis, highlight the importance of considering the downstream effects of SES declines on patient experiences regarding dialysis and access to transplant. While previous studies frequently limit their assessment of SES changes while on dialysis to employment measures (Petersen et al., 2008; Tzvetanov et al., 2014), findings from this study describe the transplant-related material losses that occur once patients are unable to work.

#### Research Question 3: Links between Pre-dialysis SES and SES declines on Dialysis

Study findings revealing that individuals with the highest SES before dialysis were most vulnerable to SES declines are valuable for understanding dialysis patient outcomes by emphasizing the role pre-dialysis exposures may have on patient experiences on dialysis. Greater SES decline observed among high SES individuals compared to low SES patients is intuitive given that this population had the greatest amount of economic resources to lose.

#### Research Question 4: Links between Declining SES on Dialysis and Transplant Pursuit

Study findings elucidated links between reduced SES and financial concerns about affording costs associated with the transplant pathway, kidney transplant surgery, and post-

transplant healthcare expenses build upon previous research findings that have also reported AA dialysis patients' concerns about kidney transplant costs (Ganji et al., 2014). Results from this study contribute new insights to previous findings; however, by emphasizing the role being on dialysis plays on losing financial resources that are needed to manage transplant-related costs. Accordingly, this study draws attention to a subset of dialysis patients, for whom financial barriers to kidney transplant may have been mitigated, should they have been able to better retain their SES and material resources while on dialysis. This finding is especially meaningful given results indicating that patients were overwhelmingly interested and willing to pursue kidney transplant.

#### Recommendations for Research and Practice

Results from this study highlight the need for additional dialysis clinic interventions and higher-level healthcare policy changes aimed to improve socioeconomic opportunities for AA dialysis patients in efforts to increase equitable access to kidney transplant. Regarding dialysis clinic interventions, workforce training opportunities, financial advising programs, and patient navigators may be crucial for helping patients to retain or increase their financial viability for kidney transplant. Various workforce maintenance and re-entry programs have been developed and have demonstrated success in improving employment outcomes for people on dialysis (Morton et al., 2017). Study findings suggest that these relevant workforce training programs should especially consider connecting dialysis patients with job-fields that are compatible with common physical limitations (e.g. weight lifting restrictions) and can be worked around routine dialysis treatment hours.

Dialysis clinics may also be ideal intervention settings for financial advising programs, given the frequency with which ESRD patients are making major financial decisions such as

selling assets, managing debt, and accruing substantial transplant-related financial obligations. Current federal guidelines require transplant hospitals to provide staff members responsible for “coordinating and clarifying financial resources for patient care” who is available to patients from the initiation of the transplant evaluation process and after obtaining a kidney transplant (Organ Procurement and Transplantation Network, 2018). However, these services may not reach many AA dialysis patients given that most do not initiate the transplant evaluation process (United States Renal Data System, 2018). Also, the national recommendations for these efforts focus more narrowly on managing transplant-related medical costs and standardized educational content are not clearly defined (Organ Procurement and Transplantation Network, 2018); thus there may be wide variability in the financial information ESRD patients receive. Findings from this study suggest that AA dialysis patients may greatly benefit from standardized financial advising that covers a wider range of financial topics and is offered early in the transplant pathway. Such services may be critical for dialysis patients who are considering kidney transplant given the importance of financial resources for patients’ successful transplant pursuit and their long-term financial picture post-transplant (United Network for Organ Sharing, 2011).

Patient navigators may also be a valuable resource for mitigating financial barriers to transplant. Dialysis patients connected with patient navigators who are transplant recipients have demonstrated success greater success in completing steps toward kidney transplant than individuals who did not have this support (Sullivan et al., 2012). Navigators may benefit dialysis patients by providing relatable models of successful transplant experiences, bridging patients to financial information sources when needed, and providing opportunities for more sustained social support that are important for obtaining a kidney transplant.

Improving the availability of adequate health insurance coverage may also be an important strategy for minimizing lost resources while on dialysis and eliminating socioeconomic inequities in access to kidney transplant. At the individual and organizational-level job placement programs, as described above, may help minimize patients' out-of-pocket medical expenses by bridging them to employee-sponsored, private health insurance plans. At the local and national-level, health insurance policy changes are critical for improving access to kidney transplant. Many of the financial concerns expressed by AA dialysis patients about their ability to afford medical costs associated with transplant could be resolved by enacting policies that provide dialysis patients with adequate health insurance coverage for medical treatments. Previous studies have advocated for expanding Medicare, to include transplant recipients younger than 65 for more than three years post-transplant, given evidence that removing access to health insurance may make life-sustaining medical treatments and medication cost-prohibitive (Ganji et al., 2014; Gordon, 2006). Public health advocates have also advocated for universal health insurance coverage, which provides a more comprehensive approach to improving kidney transplant outcomes. Policies that increase health insurance coverage for all Americans may delay or prevent the onset of ESRD by facilitating healthier behaviors and access to medical care earlier in the life course.

### Limitations and Strengths

This study is not without limitations. First, this study only enrolled participants from three hospital-owned dialysis clinics in Atlanta, Georgia. Thus, findings may not be reflective of dialysis patients' experiences at other types of dialysis clinics (e.g., for-profit clinics located in different geographic locations). Second, this study relies primarily on ESRD patients' first-person accounts to answer its research questions. A weakness of self-reported data sources is

their susceptibility to social desirability and recall bias. However, this study considers the risks of response bias to be far outweighed by the benefits of learning from ESRD patients' primary accounts of their various experiences on dialysis. It is unlikely that more objective collection methods could better capture this data. To maximize the credibility of the data, we triangulated findings reported by ESRD patients on important clinical outcomes of interest (including reports of whether patients expressed interest in, received a referral for or were waitlisted for transplant) with medical record data from respective dialysis clinics. Third, this study limited the scope of its research questions to patients' socioeconomic situations one year before dialysis until the present. While exploring earlier years before beginning dialysis were beyond the scope of this study, it is likely that better understanding patients more extended financial and health histories would add to findings related to SES decline. Given that many patients described being sick or disabled the year before they began dialysis, it is likely that they too experienced a health-related socioeconomic decline, but earlier in life, perhaps the result of a different disease or complications related to chronic kidney disease.

Despite the limitations described above, there are also substantial strengths in this study's emphasis on better understanding AA dialysis patients' experiences with declines in SES and material resources while on dialysis and how they are linked to kidney transplant pursuit. This qualitative design is a major attribute of this study as in-depth interviews findings were more adept in capturing the complexities inherent in the details of patients' financial situations before and after transplant and their thoughts about on kidney transplant pursuit.

This work is innovative and important for the ways in which it speaks to the ongoing need for multi-level interventions to promote racial and socioeconomic equity in access to kidney transplant. This study applied qualitative study methods to explore its research questions

which enhanced its capacity to provide rich explanatory descriptions of the complex relationships between socioeconomic changes experienced on dialysis and transplant pursuit. Results identify modifiable social factors associated with transplant pursuit and highlight opportunities for supportive interventions. Findings elucidated from this study are useful for informing health disparities research and organization-level interventions aimed to promote equity in access to kidney transplant

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## Conclusion

### I. Main findings

This dissertation addressed racial and socioeconomic disparities in access to kidney transplant by elucidating knowledge about neighborhood, social network and individual-level socioeconomic factors associated with transplant pursuit among predominantly AA ESRD patients undergoing dialysis. Chapters Two, Three, and Four described research studies that (1) quantitatively measured associations between neighborhood-level socioeconomic characteristics of dialysis patients' physical, social, and service environments and kidney transplant wait-listing rates, using time-to-event cox regression modeling and (2) qualitatively elucidated how functions of dialysis patients' social networks (i.e. social influence, social undermining, social companionship, and social support) and (3) experiences with socioeconomic declines while on dialysis influence patients' interest in and pursuit of kidney transplant.

Research findings identified modifiable mezzo, micro and individual-level factors that facilitate or impede patients opportunities to pursue kidney transplant ( Figure 1.5) (Glass & McAtee, 2006). Findings were used to describe opportunities for supportive interventions at higher levels of the socioecological model. This theoretical approach is guided by evidence that interventions that address higher level social determinants may provide greater population impact while minimizing the individual effort required improve health behaviors (Frieden, 2010). In interpreting findings, we apply a concurrent triangulation methodological approach whereby qualitative key informant interviews and quantitative secondary data collection were conducted and analyzed within the same study period and prioritized equally in helping to explain different aspects of the relationships examined (Creswell & Plano Clark, 2007).

The following section presents main study findings related to social and economic factors associated with kidney transplant pursuit. Findings are organized in response to this dissertation's three study aims described in Chapter One.

Aim 1: Identify socioeconomic characteristics of dialysis patients physical, social and service environments associated with waitlisting for kidney transplant.

Chapter Two examined the ways in which neighborhood socioeconomic characteristics visible in patients physical, service and social environments are associated with dialysis patients' rate of being waitlisted for kidney transplant. Quantitative analysis conducted with a study sample of 1118 predominantly AA dialysis patients yielded several key findings. Unadjusted bivariate analysis revealed that on average, patients who were not waitlisted for kidney transplant lived in neighborhoods with higher concentrations of vacant homes and single-parent families. Data analysis assessing relationships between high concentrations of unemployed residents and waitlisting yielded effect sizes that support a similarly inverse relationship but were not statistically significant.

We found that patients who lived in neighborhoods with higher concentrations of vacant housing and single-parent families were less likely to be waitlisted for kidney transplant. Adjusted sequential cox modeling showed that these relationships remained statistically significant for vacant housing and single-parent families after controlling for patient-level demographics, ESRD etiology, treating dialysis clinic and socioeconomic characteristics. Similar relationships were observed between higher neighborhood rates of medically uninsured residents and patient waitlisting but were not statistically significant.

Aim 2: Describe patients' social networks while on dialysis and how they shape pursuit of transplant

Chapter Three described links between AA dialysis patients social network functions (social influence, social undermining, social companionship and social support) and kidney transplant pursuit.

*Interest in Transplant.* Study findings indicate that participants most patients (81%) wanted to pursue kidney transplant despite few participants (16%) demonstrating success in progressing to the kidney transplant waiting list. Interview findings revealed participants' willingness to pursue a kidney transplant as complex, dynamic processes, often guided by external forces.

*Social Influence.* Qualitative findings indicated that family members and transplant recipients were key resources for social influence. Transplant recipients were especially persuasive in encouraging interest and confidence in pursuing transplant by providing verbal encouragement and physical evidence of the benefits of transplant. These findings are supported by existing evidence that positive attitudes and social norms are associated with increased intentions to perform health behaviors (Ajzen, 1991) and that having a greater number of loose social ties improves access to transplant (Clark et al., 2008).

*Social Undermining.* Qualitative interview findings did not frequently describe social undermining as guiding patients' thoughts or actions towards kidney transplant. Instead, patients' commitments to remaining positive demonstrated resilience, which may help to mitigate the impact of negative transplant stories they encounter at the dialysis clinic. It is also possible that participants' commitments to staying positive lead to underestimating or underreporting how negative stories they hear impact their attitudes and actions toward kidney transplant.

Quantitative findings described in Chapter Two suggest that patients receiving care at this study's three dialysis clinics are largely lower SES AA patients who live in lower SES neighborhoods and thus may be at greater risk for poor health outcomes post-transplant (Patzner et al., 2009; United States Renal Data System, 2018). These findings harken the need for research examining the ways in which adverse transplant experiences influence clinic and community beliefs about kidney transplant.

*Social Companionship.* Local family members and dialysis patients were primary sources of companionship and quality time, which were described as important supports for pursuing kidney transplant. However, qualitative interview findings revealed several barriers (e.g. long hours spent on dialysis) to maintaining existing relationships and creating new ones while on dialysis. Quantitative data presented in Chapter Two findings further suggests that most dialysis patients were not married and lived in neighborhoods with high concentrations of single parent families. Challenges with sustaining companionship are concerning given evidence from this study that spending time with loved ones encouraged transplant pursuit.

Dialysis patients also served as important companions for many patients. These relationships were easily accessible while patients were receiving care in the dialysis clinic and contributed to the dense, heterogenous social networks. Still, they provided only limited engagement for many when they did not extend beyond the dialysis clinic or were often cut short due to patient illnesses or premature deaths.

*Social Support.* Qualitative data revealed that family members were especially valuable social network members in providing non-monetary support important for transplant pursuit. Patients often had greater difficulty in identifying resources for financial instrumental support. Patients found healthcare professionals to be common resources for informational and appraisal

support related to kidney transplant. However, information and advising received from providers may be diminished by misinformation received from transplant recipients and by medical distrust.

Aim 3: Describe patient experiences with declines in socioeconomic status while on dialysis and how they shape pursuit of kidney transplant.

Chapter Four described associations between AA dialysis patients experiences with socioeconomic declines in SES and resources while on dialysis and kidney transplant pursuit. Findings revealed that for most patients, being on dialysis was marked by declines in SES and lost material resources. Patients described losing employment, income and financial stability, adding to previous studies that also describe socioeconomic declines associated with ongoing dialysis care (Murray et al., 2014; United States Renal Data System, 2018).

Evidence of lost employment among dialysis patients who desire to work is concerning given evidence that unemployment is linked to reduced access to kidney transplant. This matters at an individual level because being unemployed may limit patients' income opportunities, which can make it challenging for patients to demonstrate their ability to afford future transplant related medical costs. Qualitative data from Chapter Three suggest that unemployment may pose additional concerns by further limiting patients' social networks. Patients who no longer work may lose social network members who otherwise contribute to a broader more diverse social network that supports access to kidney transplant.

Chapter Four findings revealed that patients' experiences with lost resources including transportation, stable housing, and private medical insurance, were often the results of SES declines. Experiences with lost transportation and instable housing may also help to explain patients' experiences with difficulties maintaining social companionship (as described in Chapter



Three). Patients who lose their cars or can no longer afford public transportation may further experience difficulties with traveling to family events or visiting friends. This finding supports previous study findings suggesting that being on dialysis is commonly linked to reduced participation in life activities (Purnell et al., 2013).

Evidence of housing instability due to SES declines may contribute to patients living in neighborhoods with lower SES characteristics compared to state averages (described in Chapter Two). Also, it may provide context for quantitative data suggesting that although most patients are not married, they do not live alone. Instead, many patients describe having to move in with family members while on dialysis for financial or health reasons. Finally, findings from Chapter Four suggest that individuals with the highest SES before beginning dialysis had the greatest risk of experiencing SES declines. Descriptions of financial challenges were pervasive in interview discussions as were concerns and uncertainty about their ability to afford transplant.

## II. Evaluation of Research

### Limitations

This dissertation design is not without limitations. Quantitative methods were applied using a retrospective, cross-sectional design, which limits opportunities to establish temporality and thus limits findings from establishing causality (Menard, 2008; Salazar et al., 2011). For example, while associations were observed between neighborhood-level socioeconomic characteristics and pursuit of transplant, we are unable to conclude whether these community exposures are causing the observed outcomes or if patients' experiences with pursuit of transplant are somehow influencing where people live. However, the influence of SES on ESRD, in particular, has been supported by this dissertation's qualitative findings and by observations of

a gradient relationship across race and sex groups whereby higher SES predicts lower risk for the disease (Ward, 2008). It is also possible that both of these phenomena are occurring.

Both quantitative and qualitative data were linked to dialysis patients who received treatments from a small group of three similar dialysis clinics. All three dialysis clinics, which were narrowly located in the Atlanta metropolitan area, were not-for-profit organizations, and were operated by the same hospital. These clinic similarities may reduce the generalizability of this study for ESRD patients who receive dialysis care in other geographical regions or for-profit clinics. Additionally, this study's use of a small number of similar clinics settings precluded opportunities to examine relationships between dialysis clinic characteristics and patient outcomes.

Qualitative research described in Chapters Three and Four relied primarily on ESRD patients' first-person accounts to answer its research questions, which can be susceptible to social desirability and recall bias. This approach reflects this study's prioritization of patients' personal perspectives for interpreting their progress toward transplant. Thus, we consider the risks of response bias to be outweighed by the anticipated benefits of learning from ESRD patients' primary accounts of their various experiences on dialysis. It is unlikely that more objective collection methods can better capture this type of data. To maximize the credibility of the data, we triangulated findings reported by ESRD patients on important clinical outcomes of interest (e.g. transplant center referral status, kidney transplant waitlisting status) with information accessed from medical records and clinic social workers.

This dissertation's theoretical approach emphasized the importance of examining social and economic determinants located at various levels of the social ecological model. However, this study's research was limited to assessing individual, intrapersonal, and neighborhood

factors. Although beyond its scope, this study would be enhanced by further research examining social determinants from other social ecological levels including dialysis clinic characteristics, transplant center features, and state and national healthcare policies. Similarly, interviews conducted with social network members (e.g. family members, nephrologists, and dialysis social workers) may provide additional context to patients experiences on dialysis and access to transplant. These groups emerged as important sources in qualitative interview discussions, supporting the need for such inquiry in future studies.

### Strengths

Despite described limitations, there are significant strengths of this dissertation project. Findings identified numerous multi-level, modifiable social and economic factors associated with kidney transplant pursuit, thus highlighting opportunities for future interventions that maximize community impacts of improving access to kidney transplant (Frieden, 2010). This study's use of both quantitative and qualitative methods resulted in rich explanatory descriptions regarding the relationship between dialysis patient's social and economic factors and pursuit of transplant.

This study dissertation additionally explored novel research questions. Chapter Two's exploration of the physical, social, and service environment was unique given this dissertation's consideration of neighborhood-level features of patients' home environment, whereas previous studies have focused more commonly on individual level characteristics, or dialysis clinic neighborhoods(L. Plantinga et al., 2014). This project's use of physical, social and service environment as constructs for understanding neighborhood deprivation, provides useful recommendations for future projects (Adler & Ostrove, 1999). Chapter Three adeptly identified various social network functions associated with kidney transplant using in-depth interview data

collection methods; whereas previous research has overwhelmingly focused on social support and frequently overlooks financial resources accessed through patients' social circles.

### III. Implications for Public Health Research and Practice

Research findings presented in this dissertation offer several implications for future public health research and practice.

#### Research Implications

Regarding research implications, study findings highlight the need for additional methods for measuring dialysis patients' interest in kidney transplant. This study found that this information was difficult to capture for various reasons. Within the participating dialysis clinics, patients' interest in kidney transplant was recorded in patient medical records by dialysis clinic social workers. Patients waitlisting status was noted as "declines transplant information" if they indicated to social workers that they were not interested in transplant. While there may be similarities in the ways in which each clinic's staff members ask about patients' interest in transplant, because they are all owned by the same hospital, there are no national standards for how to ask or report this variable (Organ Procurement and Transplantation Network, 2018). Findings from my mixed methods research demonstrate concerns with this, because patients' interests in transplant were often complex and dynamic constructs. Most patients wanted a transplant but did not actively pursue a kidney transplant because of real or perceived barriers to making progressive steps in the transplant pathway. However, these nuances were seldom captured in my quantitative survey items or by dialysis clinic electronic medical records

Patients' interest in kidney transplant was additionally challenging to measure because it changes over time. Interview findings from Chapter Three revealed evidence that these changes are often not easily captured at the dialysis clinic level. These findings harken the need for a

validated multi-item index for assessing patient interest at routine time intervals. Such an index would benefit from asking about patients' willingness, self-efficacy, reasons for interest or disinterest and perceived barriers related to transplant. Growing collaborations between dialysis clinics and transplant centers are promising (United States Renal Data System, 2018). Creating a validated measure for assessing patient interest would be a valuable contribution to such projects.

My research findings additionally demonstrate the need to further explore the cyclic relationship between illness and poverty identified by a feedback loop in this dissertation's theoretical model (Table 1.5). Qualitative data described in Chapter Four highlighted a group of patients that did not experience declines in SES while on dialysis, largely because prior to beginning dialysis they were experiencing very poor financial situations and poor health. Findings from this dissertation suggest that these two experiences are very much related. Many patients who had serious health issues (including diabetes or high blood pressure) prior to beginning dialysis were experiencing physical challenges that led to financial instability when they could not work consistently or accrued debt from medical treatments. Employment or financial instability then contributed to challenges with managing health conditions if they could not afford treatments. More research that examines the patterns of economic and health challenges in the years leading up to dialysis is needed to identify earlier opportunities to prevent ESRD and ensure that patients progress to ESRD as viable candidates for kidney transplant when possible

### Practice Implications

Findings from this study highlight numerous intervention opportunities for improving access to kidney transplant for AA dialysis patients. The following section describes practice recommendations at various levels of the socioecological framework (Glass & McAtee, 2006)

Findings from all three dissertation projects demonstrate the need for improved access to reliable medical insurance coverage in the U.S. Health insurance policy changes are critical for providing equitable opportunities for ESRD patients to pursue kidney transplant. During qualitative interview discussions, many of the financial concerns expressed by AA dialysis patients about their ability to afford medical costs associated with transplant, could be resolved by enacting policies that provide dialysis patients with adequate health insurance coverage for medical treatments. Previous projects have advocated for expanding Medicare to include transplant recipients younger than 65 for more than three years post-transplant, given evidence that removing access to health insurance may make life-sustaining medical treatments and medication cost-prohibitive (Ganji et al., 2014; Gordon, 2006). Public health advocates have also championed for universal health insurance coverage, which provides a more comprehensive approach to improving kidney transplant outcomes. Policies that increase health insurance coverage for all Americans may delay or prevent the onset of ESRD by facilitating healthier behaviors and access to medical care earlier in the life course.

Study findings revealed several opportunities for strengthening dialysis clinic policies so that they can more successfully prepare patients for kidney transplant pursuit. One opportunity for growth is to extend some parts of the transplant evaluation process to dialysis clinics. For example, dialysis clinics may be ideal locations for facilitating required transplant evaluation information sessions. Allowing patients to begin their evaluation process at the dialysis clinics they already frequent may promote health equity by reducing the impact of socioeconomic challenges (e.g. transportation) which can be significant barriers.

Dialysis clinics may also be ideal interventions setting for individual and intrapersonal-level strategies for improving access to kidney transplant. For example, interventions that

provide loved ones with greater information about kidney transplant may strengthen social support provided by family members and create opportunities for maintained social companionship. And, bridging patients to new resources for information and support for pursuing kidney transplant, including patient navigators, successful transplant recipients, and mental health therapists and may also be important (Rodrigue et al., 2011; Sullivan et al., 2012). For example, intervention strategies that connect patients with patient navigators to assist with taking steps toward kidney transplant and policies that make financial coordinators available at transplant centers to assist with managing insurance processes may be especially useful in reducing barriers to transplant for patients with limited social support (Organ Procurement and Transplantation Network, 2018; Sullivan et al., 2012).

#### IV. Conclusion

This dissertation project describes research that is innovative and important for the ways in which it elucidates multi-level factors associated with socioeconomic disparities in access to kidney transplant among predominantly African American dialysis patients. Research questions emphasized modifiable factors that shape patient behaviors. This project generated new knowledge about ESRD patients experiences with neighborhood disadvantage, social network functions and socioeconomic decline while on dialysis through qualitative interviews, patient surveys, geospatial analysis and statistical analysis methods. This projects' integrated, mixed-methods design yielded rich insights that are practically useful for improving dialysis patient care and for informing interventions aimed to promote racial and socioeconomic equity in access to transplant.

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