

**THE INFLUENCE OF ILLNESS BURDEN AND SOCIAL SUPPORT ON THE  
COMPLETION OF KIDNEY TRANSPLANT EVALUATION**

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# **THE INFLUENCE OF ILLNESS BURDEN AND SOCIAL SUPPORT ON THE COMPLETION OF KIDNEY TRANSPLANT EVALUATION**

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University of Pittsburgh, 2014

Kidney transplantation is the preferred method of treatment to dialysis for end stage renal disease (ESRD) because of its many proven benefits over dialysis treatment. Patients interested in kidney transplantation must undergo a kidney transplant (KT) evaluation to determine their medical and psychosocial eligibility. A timely completion of the KT evaluation is critical for prompt listing for or the receipt of a KT. However, ESRD patients suffer from significant illness burden that interferes in their participation of life activities, which can affect their completion of KT evaluations. At the same time, the presence of social support is known to abate symptom burden and the perception of illness burden. This implies that social support has the potential to facilitate completions of KT evaluations by moderating illness burden.

This novel study is the first to examine how social support buffers illness burden in affecting KT evaluation completion. This quantitative study involves 1,130 study participants recruited from the Starzl Transplant Institute of University of Pittsburgh Medical Center. The goals of this study are 1) to understand how demographic factors (age, gender, race and income), illness burden and social support independently affects time taken to complete KT evaluation, and 2) to assess how these factors interact in influencing time to complete KT evaluation.

The hypothesis that social support buffers illness burden in the completion of KT evaluation was not supported. Instead social support demonstrated main effects on the completion of KT evaluation: higher level of perceived social support was associated with a

higher rate of KT evaluation completion. Older age, lower income, African American race and greater illness comorbidity were associated with lower KT evaluation completion rates. Limitations of the study include: a single-center study with non-random patient participation, a limited examination of social network based on network size, and the violation of proportionality of hazard assumption in the Cox regression analysis.

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## PREFACE

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The things you have planned for us no one can recount to you;

were I to speak of and tell of them,

they would be too many to declare.

Psalm 40:5

## **1.0 INTRODUCTION**

### **1.1 BACKGROUND AND SIGNIFICANCE**

#### **1.1.1 Prevalence of ESRD in the USA**

The United States has the third highest ESRD incidence in the world at 357 per million population and a disease prevalence at 1,901 per million population in 2011, the latter which was a 1.3% increase over the preceding year (United States Renal Data System [USRDS], 2013). As of December 31, 2011, there were 430,273 dialysis-dependent patients and 185,626 patients who received kidney transplants.

Persons suffering from ESRD require peritoneal dialysis, hemodialysis or a kidney transplant (KT) in order to live. (Section 2.1 describes the dialysis methods). The Medicare ESRD Program pays for patients' dialysis treatment and transplantation and it costs Medicare \$34.3 billion dollars—an increase of 5.4% over 2010—and accounted for 6.3% of the overall Medicare budget in 2011 (USRDS, 2013). Based on figures in the same year, it cost Medicare about \$87,945 per hemodialysis patient per year and \$71,630 per peritoneal dialysis patient per year, compared to \$32,922 annually for each transplanted patient (USRDS, 2013). With the rising incidence of ESRD, the burden on Medicare will only grow, especially considering that approximately 70% of all supported patients are on the costlier treatment: hemodialysis. Due to the proven cost-effectiveness of kidney transplantation over dialysis, promoting transplantation

will help reduce the economic burden on the Medicare ESRD Program. Further, there is superiority of KT over dialysis because it offers a better quality of life, a longer life span, less illness intrusiveness and lower hospitalization rate (Christensen & Ehlers, 2002; Pham, Pham, Pham, Parikh, & Danovitch, 2010; Pradel, Limcangco, Mullins, & Bartlett, 2003; Vamos, Novak, & Mucsi, 2009; R. A. Wolfe et al., 2000). A five-year longitudinal study on 228,552 patients demonstrated that transplanted patients had 66% lower long-term mortality risk than patients who were on the transplant waiting list (R. A. Wolfe et al., 2000). Therefore where resources and transplant candidacy criteria permit, kidney transplantation is to be recommended over dialysis treatment.

Patients interested in pursuing a kidney transplantation must undergo a KT evaluation to determine their medical and psychosocial suitability before being wait listed for a deceased kidney donor or proceeding to receive a living donor KT (Alexander & Sehgal, 2001; Pham et al., 2010; Scandling, 2005; Sterner, Zelikovsky, Green, & Kaplan, 2006). The KT evaluation consists of a battery of tests and evaluations conducted over several visits at the transplant center. A failure to complete the KT evaluation obstructs the chance for receiving a KT. In a large and representative national sample of 11,674 dialysis-dependent patients, only about a third of those with interest in KT completed the evaluations (Alexander & Sehgal, 2001). This triggers concern because it implies that majority of the ESRD patients interested in KT cannot access this optimal ESRD treatment modality due to a failure in completing this transplant prerequisite. Besides completing the KT evaluation, it is critical that it be done as short a time as possible because this translates to an earlier KT wait listing or receipt of a living donor KT (Weng, Joffe, Feldman, & Mange, 2005) A shorter waiting time before KT is associated with improved post-transplant outcomes (Meier-Kriesche & Kaplan, 2002). Healthy People 2010—the US Health

Agenda—advocated an increase of dialysis-dependent patients wait listed for KT from its 2002 rate of 16% to 66% by 2010, although this objective was never achieved (Scandling, 2005).

### **1.1.2 Barriers and Facilitators in the Completion of KT Evaluation**

Understanding the factors that potentially impede or facilitate the completion of KT evaluation will provide a basis for developing targeted interventions to improve KT evaluation completion time and rate. However it is not yet entirely understood what factors contribute to the failure in the completion of KT evaluations (Weng et al., 2005). At least one study attributed dialysis facilitative characteristics as an influence in KT completion. For example, a dialysis facility that actively engages in referring patients for KT will see more of their patients complete KT evaluations (Alexander & Sehgal, 2002). Most studies (for example Waterman et al., 2013, Weng et al., 2005) have focused on the role of patient characteristics in affecting the completion of KT evaluations, such as: demographic factors, transplant knowledge and attitudes, pre-dialysis versus dialysis-dependent, and having someone in their personal social network who informed about kidney transplantation.

This study posits that illness burden can hinder the completion of KT evaluation. Illness burden considers how a disease and/or its treatment impact the significant spheres of a person's life (Devins et al., 1983). The physical and functional deficits as well as the psychological distress concomitant with ESRD, compounded with the frequency, lifestyle restrictions and treatment-related effects of chronic dialysis treatment inflict considerable and varying illness burden on ESRD patients and affect their sense of well-being (Christensen & Ehlers, 2002; Gerald M. Devins et al., 1990; Hatthakit, 2011; Timmers et al., 2008). Because illness burden affects patients' participation in life tasks and activities, it therefore can be reasoned that illness burden affects ESRD patients in their desire and ability to complete KT evaluations. As there



are limited number of studies, it would extend our current knowledge to examine how illness burden can vary across demographic variables of age, gender, race and income.

Social support, on the other hand, is known to promote stress and illness coping (Lazarus & Folkman, 1984). There is evidence that the presence of social support abates symptom burden and the perception of illness burden (Scott D. Cohen, 2013; Kimmel & Patel, 2006) while increasing medical service utilization (S. Cohen, 2004; House, Landis, & Umberson, 1988) and facilitate prompt and successful completion of KT evaluation (Cass, Cunningham, Snelling, & Ayanian, 2003; Scandling, 2005; Steinman et al., 2001). Conversely, a lack of social support can be an impediment to the completion of KT evaluation (Kazley, Simpson, Chavin, & Baliga, 2012). Several scholars recommend the use of patients' social network and social support to increase patients' KT evaluation completion rates (Browne, 2008; Cass, et al., 2003; Lee, Arozullah, & Cho, 2004; Waterman et al., 2013; Weng, et al., 2005). Thus it can be argued that one of the best ways to increase the rate of completion of KT evaluation is by augmenting the social support of ESRD patients undergoing this process. This study adds to the current knowledge on how social support impacts the completion of KT evaluation.

The level of social support an individual receives can be affected by demographic factors such as gender, age, race and income, although there are no convergent conclusions on how they differ (Ajrouch, Blandon, & Antonucci, 2005; Cetingok, Winsett, Russell, & Hathaway, 2008; Clark, Hicks, Keogh, Epstein, & Ayanian, 2008; Cukor, Cohen, Peterson, & Kimmel, 2007; House, 1987; Turner & Marino, 1994). While women tend to receive more social support when compared to men, they also experience more psychological distress from social relationships (Turner & Marino, 1994). Generally existing data suggest that individuals from lower income group suffer from a poorer quality of social relationships and support (Ajrouch et al., 2005;

House, 1987; Turner & Marino, 1994). At least one study found that African Americans received less social support compared to whites and this had an adverse impact on the completion of KT evaluations (Clark et al., 2008). The influence of demographic factors on time to complete KT evaluation can benefit from greater elucidation through this study.

Numerous studies have documented the existence of socio-demographic disparities in influencing access to kidney transplantation, including the completion of the KT evaluation, (for example, Alexander and Sehgal, 1998, 2001; Lenihan, Hurley & Tan, 2013; Myaskovsky et al., 2012; Patzer et al., 2012; Weng et al., 2005). A review by Vamos and colleagues (2009) reported that women, the elderly and non-whites have lower access to kidney transplantation than compared to men, the younger patients and whites, even after adjusting for known confounders such as health status and illness comorbidity. Additionally, those from lower income groups and with lower health literacy have lower rates for KT evaluation and waitlisting (Alexander & Sehgal, 1998, 2001; Schold et al., 2011; Weng, et al., 2005). Studies on ethnic disparities in access to KT have predominantly focused on the African American population, with a dearth of studies on other ethnic or minority groups in the USA (Myaskovsky et al., 2007). For example, African American ESRD patients are half as likely than whites to be wait listed and about four times less likely to receive a kidney transplant (Alexander & Sehgal, 1998; Epstein et al., 2000). Compared to whites, African Americans are less likely to complete the KT evaluation, and if they do, take a longer time to complete it (Alexander & Sehgal, 1998; Epstein et al., 2000; Keren Ladin, Rodrigue, & Hanto, 2009; Waterman et al., 2013; Weng et al., 2005). Patients with low health literacy experience greater challenges navigating the steps and managing the information involved in KT evaluation, thus explaining their reduced KT evaluation and access rates (Browne, 2008; Kazley, et al., 2012; Lee, Arozullah, & Cho, 2004).

At least one study found that only half of elderly persons above 65 years who underwent KT evaluation were waitlisted, compared to about 75% of those who were under 65 years of age (Lenihan, Hurley, & Tan, 2013). The socio-demographic disparities affecting the access to kidney transplantation have implications for social work practice.

## **1.2 RESEARCH QUESTIONS AND HYPOTHESES**

There is no known study on examining the moderating effect of social support on illness burden in the completion of KT evaluation, and this study is thus novel and addresses an existing knowledge gap. The study addressed the following specific aims and hypotheses:

Specific Aim 1: Examine how ESRD patients undergoing KT evaluations differ in levels of social support and illness burden by age, gender, race and income.

Hypothesis 1a: Patients who are older, male, whites and from higher income groups have lower illness burden than those who are younger, female, non-white and from lower income groups

Hypothesis 1b: Patients who are younger, female, white and from higher income groups have bigger social networks and higher level of social support than those who are older, male, non-white and from lower income groups.

Specific Aim 2: Evaluate how illness burden affects the rate of KT evaluation completion.

Hypothesis 2: Lower illness burden is associated with a higher rate of KT evaluation completion.

Specific Aim 3: Assess how social support characteristics—social network size and perceived social support—affect the rate of KT evaluation completion.

Hypothesis 3a: A larger social network size is associated with a higher rate of KT evaluation completion.

Hypothesis 3b: Greater social support burden is associated with a higher KT evaluation completion rate.

Specific Aim 4: Determine if social support moderates the effect of ESRD illness burden on the rate of KT evaluation completion.

Hypothesis 4: Greater social support reduces the impact of ESRD illness burden and improves the rate of KT evaluation completion.

### **1.3 SIGNIFICANCE TO SOCIAL WORK PRACTICE**

Not all patients interested in KT successfully complete their KT evaluations and a failure to complete the mandatory KT evaluation constitutes a barrier in the access to kidney transplantation. The aforementioned evidence indicates that minority population sub-groups are more likely to face such a risk, exacerbated by their increased susceptibility to illness burden and reduced social support. The multi-step KT evaluation may be complex and demanding for these patients who can benefit from targeted social work interventions. For example, providing social support such as transportation access to transplant centers for the KT evaluation, can help increase their ability to complete the KT evaluation and meet this transplant pre-requisite (Clark et al., 2008). Such social action is a form of social work advocacy that promotes the well-being of disadvantaged and vulnerable sub-groups within the ESRD population, which is a focus of the social work mission (National Association of Social Workers, 2012). While this study does not evaluate socio-demographic characteristics from a health disparity perspective, outcomes from this study can contribute to social work knowledge and practice on how these less-advantaged

sub-groups may be better supported in completing KT evaluations. Further, enabling members of these population sub-groups to complete their KT evaluations upholds the values of distributive justice and social justice.

Social work evaluates the individual client in the context of his or her environment, that is, person-in-environment (PIE), which considers the inter-relatedness of the individual and his/her network or system of relationships from micro to macro levels (Streeter & Franklin, 1992). An examination of an individual's social network and social support—in relation to how they influence time to complete KT evaluation—is an assessment of PIE, and is consistent with the focus of social work practice.

Social workers act on mobilization of social resources to achieve desired change (Tracy & Whittaker, 1990). As an example of resource mobilization, outcomes from this study can guide social work practitioners in targeting ESRD patients' social networks with the aim of enhancing patients' social support and reducing their sense of illness burden to facilitate in the completion of KT evaluation. This study is therefore significant for its relevance and contribution to the mission of social work practice.

## **2.0 REVIEW OF THE LITERATURE**

### **2.1 ESRD TREATMENT MODALITIES**

For patients diagnosed with ESRD, treatment options include lifelong dialysis treatment or kidney transplantation. Two dialysis modalities are available: peritoneal dialysis and hemodialysis. Patients on peritoneal dialysis or their caregivers have to play a more active role in this daily home-based dialysis treatment. A permanent catheter is surgically-implanted in the patient's abdomen so that it can be connected to a sterile external tube which in turn is connected to a bag of dialysis solution, or dialysate. During dialysis, the dialysate—usually between 1.5 to 3 liters in volume—is introduced into the abdominal peritoneal cavity and remains for about four to eight hours, depending on the choice of peritoneal dialysis method. Excess fluid and metabolic waste products from the patient's bloodstream that pass through the semi-permeable abdominal peritoneal membrane are absorbed into the dialysate and are expelled from the body in a subsequent process that involves draining the dialysate through the catheter. Other than the times when the patient has to transfer the dialysate into/from the abdomen through the catheter, the patient remains ambulant to carry out his or her daily activities (Christensen & Ehlers, 2002). In hemodialysis, the patient is connected to a dialysis machine—which functions like an artificial kidney—through a fistula or graft catheter that is surgically created, and usually underneath the forearm. Needling of the area where the fistula or graft catheter is located allows blood to be

accessed at each hemodialysis treatment. Through the process of diffusion, metabolic waste products and excess fluids are removed from the blood and into the dialysate found in the dialysis machine. Hemodialysis occurs three times a week at a dialysis center, lasting about four hours a session and is administered by dialysis nurses or technicians (Christensen & Ehlers, 2002). In the USA, a very small group of fewer than 800 patients were on home-based hemodialysis treatment in 2011 (USRDS, 2013).

The other ESRD treatment option is kidney transplantation, where it was earlier mentioned as the recommended treatment modality. Patients who want to pursue kidney transplantation can consider living donor or deceased donor kidney transplantation. Living donor KT is recommended over deceased donor KT because it overcomes the perennial problem of kidney shortage, reduces waiting time, promises better survival rates and viability, better quality of life, is more cost-effective, and eases the societal demand on the deceased KT waiting list (Pradel et al., 2003; Yen et al., 2004). Transplanted patients require lifelong immunosuppressants to prevent rejection of the transplanted kidney.

## **2.2 ESRD ILLNESS BURDEN**

Approximately 70% of ESRD patients remain on dialysis rather than receive a kidney transplant. Even for those interested in pursuing kidney transplantation, a mere 3.3% of those who received a KT in 2011 were pre-emptive transplants, according to USRDS (2013). A pre-emptive transplant means that a patient receives a KT before he or she needs to commence dialysis treatment. In other words the majority of ESRD patients presenting for KT evaluations are undergoing dialysis treatment, with about 90% of them on hemodialysis treatment (USRDS, 2013). Factors such as degree of lifestyle impact, flexibility and independence offered by the

dialysis modality affect the patient's treatment preference, which along with medical indicators in some cases, affect the dialysis modality choice (Lee, Gudex, Povlsen, Bonnevie, & Nielsen, 2008). ESRD patients undergoing dialysis are known to be vulnerable to significant and varying degrees of illness burden due to the nature of ESRD and its treatment effects.

ESRD patients must grapple with the physical effects of kidney failure, such as diminished physical energy, increased illness symptoms like itchiness of skin, cognitive impairments from concentration difficulties and drowsiness that are induced by uremia (Devins et al., 1993; Gerald M Devins et al., 1990; Kimmel, 2000b; Weisbord et al., 2005). A systematic review of 59 studies conducted on dialysis patients confirmed that this patient population suffers from multiple disease symptoms, with more than half experiencing with fatigue, pruritus (skin itching), pain, dry skin and constipation (Murtagh, Addington-Hall, & Higginson, 2007; Weisbord et al., 2005)). Physical dysfunction is reportedly the most prevalent and debilitating illness impact with which ESRD patients must cope with (Braun, Sood, Hogue, Lieberman, & Copley-Merriman, 2012). Fatigue is partly attributable to anemia, which is prevalent in up to 80% of patients suffering from kidney failure (Merkus et al., 1999) and its high occurrence is reported in various studies (Hagren, Pettersen, Severinsson, Lützén, & Clyne, 2001; Janssen, Spruit, Wouters, & Schols, 2008; McCann & Boore, 2000). Illness comorbidity—the presence of other illnesses—is also an aspect ESRD patients have to grapple with (Janssen et al., 2008).

In addition to ESRD symptoms, the patients have to deal with its treatment-related issues. ESRD is unlike many other chronic and life-threatening illnesses because of its treatment demands, duration and frequency, and the plethora of medications that patients must consume, along with dietary and fluid restrictions (Christensen & Ehlers, 2002). These treatment-imposed lifestyle changes affect a person's relationship, occupational and social involvements (Devins,



1994; Gerald M Devins et al., 1990; Hagren et al., 2001; Kimmel, 2000b, 2001; Sensky, 1993). In qualitative studies, the theme “loss of freedom” is a recurring one among dialysis-dependent patients because of the lifestyle curtailments (Hagren et al., 2001; Hatthakit, 2011; Molzahn, Bruce, & Shields, 2008). ESRD patients also have to deal with its iatrogenic (or treatment-related) effects, such as muscle cramps (Gerald M. Devins et al., 1990). Qualitative studies have described ESRD patients as experiencing “suffering” because of their constellation of disease symptoms and illness experience (Hagren et al., 2001; Polaschek, 2003).

Psychological and emotional distress among ESRD patients is widely documented (Christensen & Ehlers, 2002; Hatthakit, 2011; Kimmel, 2001). Depression and depressive symptoms are the most reported psychological distress among ESRD patients (review by Kimmel, 2001). Anxiety is another commonly experienced psychological distress symptom (Kimmel, 2001; Sensky, 1993).

Evidently, ESRD patients have to endure considerable disease/illness burden because of the myriad of illness-related symptoms, deficits and stressors, lifestyle changes and comorbidities, or the presence of other medical conditions (Hagren et al., 2001; Janssen et al., 2008; Kimmel, 2001; Kring & Crane, 2009; Murtagh et al., 2007; Timmers et al., 2008). Disease burden or illness burden refers to the degree to which illness-induced disruptions interfere with an affected person’s lifestyle, activities and interest, and it modulates the psychosocial impact of chronic illnesses (Devins, 1994; Devins et al., 1993). Also referred to as illness intrusiveness, illness burden is not confined to the objective measures of a patient’s functional state or disease progression but is also, and to a large extent, influenced by the individual’s perception of the illness impact (Devins, 1994; Kimmel et al., 1995). Perceived illness burden varies across individuals and the disease course, and is affected by the

physiological and physical impact of illness, individual personality, life cycle, temporal factors, personal and cultural factors, and social context of the illness (Cukor et al., 2007; Devins et al., 1983; Devins et al., 1993; Kimmel, 2000b, 2001; Kleinman, 1988; McCann & Boore, 2000). Increased frequency and intensity of disease symptoms elevates perceived illness burden, and a greater perceived illness burden in turn lowers health related quality of life and satisfaction with life (Gerald M. Devins et al., 1990; Kimmel, 2001; Kimmel, Emont, Newmann, Danko, & Moss, 2003; Kimmel et al., 1995). Similarly, lower illness burden is associated with improved survival (Kimmel et al., 1998).

Disease burden correlates significantly with quality of life indicators (Devins, Beanlands, Mandin, & Paul, 1997; Devins et al., 1993; Fowler & Baas, 2005; Timmers et al., 2008). It is well documented (for example, Kring & Crane, 2009) that ESRD patients suffer from impaired health-related quality of life due to the prolonged disease and treatment course. Greater illness burden is associated with diminished emotional and psychological well-being (Christensen & Ehlers, 2002; Gerald M. Devins et al., 1990; Devins et al., 1983; Kimmel et al., 1998; Timmers et al., 2008; Weisbord et al., 2005). Also, greater illness comorbidity is associated with higher stress level (Yeh & Chou, 2007). For example, Weisbord and his colleagues (2005) examined 162 hemodialysis patients and found that the number and severity of disease symptoms experienced lowered the patients' reported quality of life score and increased their experience of depression. Timmers and colleagues' (2008) study on the association between illness perceptions and quality of life among 133 dialysis patients found that the participants reported a lower quality of life than the general population; and that perceived illness burden significantly influenced their quality of life whereby a higher sense of illness burden was linked to a lower quality of life. A study involving hemodialysis and peritoneal dialysis patients found that higher

illness burden was associated with treatment non-adherence whereby patients shortened their prescribed dialysis treatment (Kutner, Zhang, McClellan, & Cole, 2002). Further, ESRD illness burden has been reported to affect patients' significant relationships (Hagren et al., 2001), and marital and family life domains (Devins, Hunsley, Mandin, Taub, & Paul, 1997). In their qualitative study, Hagren and colleagues (2001) found that "disrupted marital, family and social life" (p. 200) was among the dominant experience of hemodialysis patients.

In international studies, Merkus and colleagues (1999) examined 226 Netherlands hemodialysis and peritoneal patients to determine how the presence of symptoms affected quality of life. They found that fatigue was the most experienced symptom in more than 80% of the patients. Illness comorbidity and increased age aggravated the sense of symptom burden which in turn lowered the quality of life. A Hong Kong study on ESRD patients receiving peritoneal dialysis, hemodialysis or on conservative treatment (that is, no dialysis treatment) reported fatigue as the most prevalent symptom with almost 74% of the study participants experiencing it (Yong et al., 2009). This study also confirmed an inverse relationship between disease burden and quality of life, and that ESRD patients suffer from a variety of disease symptoms— corroborating the outcomes of the earlier cited studies. The ESRD illness burden is significant enough to warrant the development of various measurement tools to assess its prevalence in patients' lives, for example, Kidney Disease Quality of Life Instrument (Hays, Kallich, Mapes, Coons, & Carter, 1994), Healthy Outcomes in Caring for End-Stage Renal Disease (CHOICE) Health Experience Questionnaire (Wu et al., 2001), (Weisbord et al., 2004) and Dialysis Symptom Index (Weisbord, et al., 2004).

Socio-demographic factors are known to affect illness burden (Timmers et al., 2008), although there are divergent conclusions on its impact. Lower socio-economic factors were

associated with greater disability among patients with chronic kidney disease (L. Plantinga, Johansen, Schillinger, & Powe, 2012). Illness burden can also vary across types and gender, with women generally experiencing heavier illness burden (Weisbord et al., 2005). For example, in a Taiwanese study involving 2,977 hemodialysis patients, women were found to have more stress with the physical symptoms of ESRD while the men's stress was related mainly with sexual drive and performance (Yeh & Chou, 2007). Elderly patients have more illness comorbidities and a higher illness burden than younger patients (Lenihan, Hurley, & Tan, 2013; Merkus et al., 1999). Interestingly, Kimmel and colleagues (1995) found that although older ESRD patients had higher objective measures of disease symptoms and poorer physical functioning, their subjective appraisal of life satisfaction increased: the authors opine that perception is integral to the appraisal of illness burden severity, and there is a plausibility that the elderly are better adapted to illness-related limitations and have a greater appreciation for life. At least one study found no race (African Americans versus whites) and gender differences (Kimmel et al., 2003), and yet another found age and gender difference in the perception of illness burden in (Merkus et al., 1999). The current body of knowledge is inconclusive on how demographic factors affect illness burden. Study designs and the use of different measurements for illness burden could be a plausible explanation on the varying outcomes.

Studies have found associations between perceived illness burdens and social support (review by Cukor, et al., 2007) in that lower perceived social support correlates with greater illness burden (Kimmel et al., 1998; Kimmel et al., 1995), whereas social support reduces the sense of illness burden (Kimmel, 2000b; Kimmel et al., 1995). For example, Kimmel and his colleagues (1995) investigated various factors that were potentially influential on dialysis patients' quality of life in a group of predominantly African American hemodialysis patients

from three centers in the Washington DC area. They determined that a greater perception of illness burden significantly was correlated with lower levels of social support, satisfaction with life and lower adjustment to the illness impact. In yet another study by Kimmel and his colleagues (2003) on 165 hemodialysis patients, the presence of social support improved the perception of symptom burden, quality of life and satisfaction with life. An Italian study involving 1,238 hemodialysis patients affirmed that social support from health care providers as instrumental in reducing illness burden among patients (Neri et al., 2011).

Given that ESRD patients suffer from considerable illness and treatment-related impact (Gerald M Devins et al., 1990; Hatthakit, 2011; Kimmel, 2001; Kring & Crane, 2009) and illness burden can impede participation in life activities (Devins, 1994; Devins et al., 1993), it is important to understand how illness burden may hinder the completion of KT evaluation. The scarcity of research across demographic variables on illness burden in patients undergoing KT evaluations limits our understanding in this aspect. Additionally, due to the known association between social support and illness burden, it will advance our knowledge to investigate how this relationship may affect the completion of KT evaluations.

### **2.3 KIDNEY TRANSPLANT EVALUATION**

Medicare pays for kidney transplantation and its related costs, including KT evaluation, and up to three years of immuno-suppressants. Patients can be already informed about kidney transplantation, or learn about it through their care providers and/or social network. A patient's interest in receiving a KT must precede his/her referral to a transplant center for evaluation (Alexander & Sehgal, 2001; Weng et al., 2005). A multi-disciplinary transplant team conducts the KT evaluation, also referred to as the pre-transplant evaluation or workup, to assess the

patient for medical and psychosocial fitness for kidney transplantation (M. S. Fisher, 2006; Maldonado et al., 2012; Schold et al., 2011). Clinical practice guidelines for the assessment of medical, surgical and psychosocial suitability of transplant recipient candidates have been proposed by the American Society of Transplant Physicians since 1994 and are revised as transplant medicine develops (Kasiske et al., 1995; Scandling, 2005). While these guidelines can be helpful in providing the scope for evaluation, transplant centers in the USA vary in their KT evaluation practice (Scandling, 2005). Typically, the KT evaluation requires a patient to make a few visits to the transplant center for a series of physical, medical and psychosocial assessments. The medical evaluation involves the patient providing a medical history and undergoing laboratory and radiological investigations (Gallon, Leventhal, & Kaufman, 2002). Additional tests may be ordered upon assessment by the transplant physicians (Weng et al., 2005). The psychosocial component of the KT evaluation is conducted either by a transplant social worker, transplant psychologist and/or transplant psychiatrist (Maldonado et al., 2012). The psychosocial evaluation focuses on the patient's psychological, psychiatric and social functioning, and risk factors that may reduce the success of kidney transplantation. It also assesses the level of resources, familial and social support that can enhance the patient's coping in the pre and post-transplant phases (Kasiske et al., 1995; Maldonado et al., 2012). Another component of the psychosocial evaluation is the determination of the patient's ability to provide informed consent, which would require the patient to demonstrate competence in decision making and voluntariness in his/her decision to receive a KT (M. S. Fisher, 2006). A patient may be rejected for kidney transplantation because of medical ineligibility as surfaced by the KT evaluation outcome. Failure to meet the psychosocial criteria can also render a patient ineligible for KT, such as a history of medical non-adherence and lack of social support (Scandling, 2005).

The KT evaluation is but one component of a multi-step process for the receipt of a KT, which Alexander and Sehgal (2001) identify as: (A) interest in and medical suitability for KT, (B) definite interest in KT, (C) completion of KT evaluation, and (D) ascension on the KT waitlist and receipt of a KT. The authors conducted the first systematic study involving 4,579 dialysis patients to investigate failure in the completion of the KT process. They determined that the chief reason for failure to complete any particular step in the KT evaluation was because patients remained stationary at that step—regression to an earlier step or death was not the main causes. For example, a patient undergoing KT evaluation (step C) did not successfully advance to waitlisting for a KT (step D) because the patient remained stuck in this KT evaluation stage, not because the patient went backward in the process and reconsidered if KT was the treatment he/she wanted to pursue. According to the authors, patients remaining stationary at steps A and D would be unsurprising because those in step A were either medically suitable or uninterested in KT. Unless there was a change in their medical condition or KT interest, they would not proceed to the next step. Since Step D consisted of waitlisted patients, they would inevitably remain at that step until a suitable kidney was available. The authors attributed the stagnation at steps B and C to inefficiencies in the transplant process. The implication of this knowledge is that interventions must be targeted to prod patients who remain stationary at stages A, B and C to advance to the succeeding stage so that they can be waitlisted for KT, if found suitable. For example, providing patient education might convert some patients at step A to become interested in KT, hence progressing to step B. Even at step B, patient education session remains necessary so that their initial interest in KT would become a definite one.

It is imperative that the evaluation be successfully and promptly completed. This is because an earlier completion of KT evaluation leads to earlier waitlisting, hence an earlier

opportunity for receiving a KT (Weng et al., 2005). The waiting time for a KT while on dialysis affects the survival of the transplanted kidney and of the patient; and a longer waiting time for a KT increases post-transplant mortality and the risk of transplant rejection (Meier-Kriesche & Kaplan, 2002; Meier-Kriesche et al., 2000). While dialysis offers ESRD patients a survival chance, it is not a perfect remedy. Patients with a longer dialysis-dependent waiting time for a KT suffer more from dialysis-related health detriments: chronic dialysis is known to alter patients' biochemistry that increases cardiovascular damage and mortality (Meier-Kriesche & Kaplan, 2002; Wang et al., 2004; Yeun, Levine, Mantadilok, & Kaysen, 2000; Zimmermann, Herrlinger, Pruy, Metzger, & Wanner, 1999). Dialysis patients also suffer from compromised nutritional status consequence to their lifestyle changes and the effects of the disease (Kaufmann, Smolle, Horina, Zach, & Krejs, 1994). Therefore, patients who are able to more quickly complete the KT evaluation have survival advantage over patients who took a longer time to complete their KT evaluation. However, patients' desire to complete the transplant evaluation process can be hampered by fears of being turned down for transplant eligibility (M. Dew et al., 2002; Kazley et al., 2012; Rainer, Thompson, & Lambros, 2010; Sullivan et al., 2012) or having known or heard of someone who has a failed organ transplantation (Sensky, 1993). Kazley and her colleagues (2012) examined the reasons for failure to complete KT evaluations in 83 patients comprising of 49 (59%) females, 31 (37.3%) males and the remaining three who did not indicate their gender. Of these participants, 12 (14.5%) were white, 66 (79.5%) were African American, and the remaining being Hispanic. The patients ranged from 20-78 in age, with the mean age of 53.5 years. Their study reported that doubts on meeting the medical eligibility for KT was the chief reason for evaluation attrition, followed by fear of KT surgery and concerns regarding post-transplant medication affordability. The authors believe that poor provider communication,



misinformation, lack of health literacy and erroneous beliefs about KT surgery likely contributed to the patients' beliefs and behavior. It is also known that the KT evaluation phase is punctuated with mixed feelings of hope for a new lease on life through transplantation, anxiety regarding timely availability of an organ, surgical risk if transplanted, and ambivalence (Rainer et al., 2010). A study involving 518 patients who presented for KT evaluation found the presence of depressive symptoms and anxiety in about 15% and 7.6% of the candidates respectively (Kuntz & Bonfiglio, 2011). Although these rates were lower than expected, the authors speculated that it might be attributed to patients desiring to promote a more positive image to enhance their chance for psychosocial eligibility for KT.

Besides patients' feelings and concerns regarding kidney transplantation and eligibility, socio-demographic differences of age, gender, race and income have been shown to influence KT evaluation completion time (Alexander & Sehgal, 1998, 2001; Epstein et al., 2000; Kazley et al., 2012; Patzer et al., 2012; Schold et al., 2011; Waterman et al., 2013; Weng et al., 2005). For example, a university hospital transplant center's study compared 175 pre-dialysis and dialysis-dependent patients and their rates of completion for KT evaluations. African Americans were significantly slower than whites to complete the evaluations (Weng et al., 2005). Schold et al. (2011) investigated 3,029 patients referred to University of Florida transplant center to elucidate factors that affected progression through the transplantation process. Among their findings, they reported that for patients who took over a year to complete their KT evaluations, they were more likely to be African American, from lower income groups and without private insurance. A recent study examined KT evaluation completion rate within one year among 695 white and African American ESRD patients who presented for their evaluations at a university hospital transplant center. Results showed that compared to whites, African Americans were less likely

to complete their KT evaluations within a year and had less knowledge about kidney transplantation (Waterman et al., 2013). Patzer and colleagues (2012) corroborated that African Americans were significantly less likely than whites to advance through the kidney transplantation steps. Their conclusion was based on a sample of 2,291 patients referred to a transplant center in the southeastern region of USA. It has been posited that religious objection and cultural factors, such as medical mistrust and perceived racism and discrimination in the healthcare system affect the time it takes for African Americans to complete KT evaluations and be accepted for a KT (Klassen, Hall, Saksvig, Curbow, & Klassen, 2002; Myaskovsky et al., 2012). Numerous studies, e.g., Ayanian et al., (1999) have reported a lack of trust among African American patients towards their doctors or the healthcare system. The Tuskegee Study has been often cited as the source for such mistrust (Myaskovsky, 2012). African American patients who reported experiencing more lifetime racial discrimination are less likely to report desiring a kidney transplant and are less likely to be placed on the transplant waiting list (Klassen et al., 2002; Myaskovsky, 2012). Another plausible explanation is that lower income African American ESRD patients are less likely to find accurate KT information and instrumental social support that can otherwise advance their completion of KT evaluation (Browne, 2008).

The above discussions highlight some of the psychological, emotional and cognitive challenges ESRD patients face when undergoing KT evaluations. As a transplant prerequisite, a failure to complete the KT evaluation thus becomes a barrier in the access to KT (Weng et al., 2005). The KT evaluation process may be tedious and demanding for some, especially for those with limited resources. There is evidence that social support can aid patients in overcoming these challenges to achieve timely and successful completion of the KT evaluation (Cass et al., 2003; M. S. Fisher, 2006; Kazley et al., 2012; Scandling, 2005; Steinman et al., 2001). For

example, informational support can provide patients with the necessary and correct information about kidney transplantation that will enhance their knowledge about navigation of the KT pathway (Browne, 2008; Waterman et al., 2013). Also, patients may not be able to complete the KT evaluation because of a lack of instrumental support, for example, needing child care and transport arrangements in order to attend KT sessions at the transplant center (Browne, 2008; Kazley et al., 2012; Scandling, 2005; Waterman et al., 2013). Emotional support provides an avenue for patients to discuss KT concerns and anxiety (Schold et al., 2011). In a recent and only known randomized controlled trial involving 167 participants from 23 Ohio hemodialysis facilities, three KT recipients functioned as navigators and guided KT evaluation candidates in the intervention group through the process. Those in the intervention completed twice as many of the KT evaluation steps than those in the control group, and those with a navigator were twice more likely to complete the KT process and be waitlisted for KT. Outcomes of the study demonstrated that receipt of social support promoted progress through the KT evaluation (Sullivan et al., 2012). In addition to leading patients through the progressive steps in KT evaluation, social support can potentially ameliorate ESRD disease burden, which this study posits as a likely impediment to the completion of KT evaluation.

## **2.4 SOCIAL SUPPORT AND HEALTH**

### **2.4.1 Early Works on Social Support and Health**

There is a prodigious volume of research on the benefits of social relationships on health (Berkman, Glass, Brissette, & Seeman, 2000; House, 1987; House, Landis, et al., 1988; Turner & Marino, 1994; Uchino, 2009). The earliest known study was by Durkheim (1897/1954) who found that unmarried individuals and people with less social integration had higher suicide risk

than those who were married or who were more socially integrated (House, Landis, et al., 1988). The assertion was that the absence of social support might have fatal consequences.

Few studies related to social support punctuated the period thereafter until the mid-1970s when the concept “social support” first emerged from mental health literature (House, Landis, et al., 1988). Caplan (1974) noted in his thesis that people engage in various relationships to meet their needs, enhance their sense of well-being and cope with the environment; and that such relationships—formal and informal, and ranging from personal, family to community—form a support system for individuals. From his observations that some individuals in society might have inadequate support from their personal network, he exhorted mental health professionals to buttress existing and develop new support programs and systems in contributing to the people’s mental health development (Caplan, 1974). In the Report to the President from the President’s Commission on Mental Health (1978), the authors concluded that in dealing with problems, people sought help and support from their “personal and social networks of families, neighbors and community organizations” (p. 14). The task force observed how community social support programs availed by employers, self-help groups, schools, health services, churches, criminal justice systems, etc., supplemented the personal support systems of affected individuals in dealing with their situations. Mental health professionals were the early advocates for increasing social support levels to improve coping ability in people.

Happening at a time proximal to what the mental health community was advocating regarding social support, two independent seminal lectures by physician epidemiologists John Cassel and Sidney Cobb examining the connection between social relationships and physical health ignited the interest in this field (Christakis, 2004; House, Landis, et al., 1988; House, Umberson, & Landis, 1988). Cobb (1976) evaluated existing scholarly work documenting the

benefits of social relationships on physical health, particularly when individuals were confronted with stressful life events. Cassel (1976) inferred from epidemiological data that the presence of social relationships had profound effects on an individual's resistance to environmental disease agents. Both concluded that social relationships were conduits through which individuals can receive support and its concomitant health-enhancing effects. (House, Landis, et al., 1988; House, Umberson, et al., 1988). Therefore, beginning from the mid-1970s interest in and attention to social support and its beneficiary effects on health—physical and mental—gained momentum.

Despite its sociological roots, contributions from health science researchers have dominated this field of study (Christakis, 2004; House, Landis, et al., 1988). Research on social support and health has burgeoned: beginning with only two articles published annually in the 1970s, the number grew to 43 by 1981 (House, Umberson, & Landis, 1988), and in the eight years between January 1984 and February 1992, there were 4,274 publications on this topic in medical and social science journals and the numbers continue to grow (Callaghan & Morrissey, 1993). Pioneering and early studies demonstrated that social network size was a significant predictor for mortality (Berkman & Syme, 1979; Schaefer, Coyne, & Lazarus, 1981). Investigations on the impact of social support on health, mortality and diseases have continued to corroborate the benefits of social support on the cardiovascular, endocrine and immune systems (Uchino, Cacioppo, & Kiecolt-Glaser, 1996), with an ever-expanding study of these concepts to various diseases, including diabetes, kidney failure, HIV, cancer, cardiovascular health, and mental health (Reblin & Uchino, 2008; Thong, Kaptein, Krediet, Boeschoten, & Dekker, 2007). Studies have also been conducted in different geographic settings, socio-economic groups and ethnicity (Patel, Peterson, & Kimmel, 2005).

## **2.4.2 Social Support Concepts**

The proliferation of social support and health studies is dented from a lack of consensus among scholars on the exact definition of social support. The terms social support, social network and social integration or isolation and social relationships have been used interchangeably—even though they vary conceptually—to describe the existence, size, quality and frequency of social relationships (Berkman et al., 2000; S. Cohen, 2004; S. Cohen & Syme, 1985; House, Landis, et al., 1988; House, Umberson, et al., 1988). Further, existing studies employ different measurements of the varying social constructs under the rubric of social support (S. Cohen, 1988, 2004; House, Umberson, et al., 1988). Succinctly, social support can be examined from either or both the structural and functional perspectives (S. Cohen & Syme, 1985; S. Cohen & Wills, 1985; Reblin & Uchino, 2008). The structural approach focuses on assessment of social network characteristics and is often deemed as the objective (and quantitative) measure of social support—even though it mainly relies on self-report—such as the existence, number and the inter-connectedness of social ties an individual has, memberships in groups and social integration (Christakis, 2004; Reblin & Uchino, 2008). The structural approach therefore examines social integration and social isolation (House, Umberson, et al., 1988). The functional approach is concerned with how social relationships serve actual functions, like the provision of support, or the types of transactions or support provided by social ties (Christakis, 2004; Reblin & Uchino, 2008) The functional perspective relates to an individual’s perceived or actual social support received (S. Cohen & Syme, 1985; Reblin & Uchino, 2008). A brief explanation on core social support-related constructs in health—distilled primarily from earlier works when they were initially conceptualized—follows.

### **2.4.3 Social Integration and Social Isolation**

Social integration and social isolation refers to the existence or quantity of social relationships (House, Kahn, McLeod, & Williams, 1985; House, Umberson, et al., 1988), or the degree of an individual's participation in a broad range of relationships (Brissette, Cohen, & Seeman, 2000). Social relationships can be categorized according to type (e.g. marital, colleague) and frequency of contact (House et al., 1988). The number of social ties and the frequency of contacts an individual has with such ties determine the degree of the individual's social integration or isolation although they are not indicative of the magnitude of social functions these ties may provide. The works of Durkheim (1897/1951) and Berkman and Syme (1979) are examples of the impact of social integration and isolation on health. The impact of social integration on health is the most studied aspect under the rubric of social support, and numerous studies have corroborated that greater social integration is associated with lower mortality risks (S. Cohen, 1988).

### **2.4.4 Social Network**

Social network is the web of relationships which an individual is connected with (Heaney & Israel, 2002), and it is through an individual's social network that resources flow and are exchanged among members (Berkman et al., 2000). Social network analysis considers the number of relationships an individual has (network size), the types of social ties, the strength between ties (density) and the interrelationships among the ties (House et al., 1985; House, Umberson, et al., 1988; Smith & Christakis, 2008). Social networks can also be analyzed for multiplexity (the number of types of support flowing through the ties), reciprocity (the exchange of transaction or support between the individual and the social ties), duration (length of

acquaintanceship between ties), frequency, and homogeneity (the degree of similarity among the ties in the social network) (Israel, 1982).

Analysis of social networks has been used in understanding the spread of infectious diseases, lifestyle behavior such as obesity, smoking, and health-related emotional states like depression, happiness and suicidality (Smith & Christakis, 2008). An observation in social network analysis is the evidence of homophily: individuals are drawn to becoming acquainted with others who are similar to themselves, including along demographic dimension (McPherson, Smith-Lovin, & Cook, 2001). For example, a poor person is likely to have poor people in his or her social network. Similarly, a rich person is likely to be connected to other rich people in his or her social network. One effect of homophily is that information, behavioral and cultural material that flow within the network, tends to be limited or similar (McPherson et al., 2001). Granovetter (1973) posits that the limited information that flows within one's homogenous network can, however, be overcome and diversified through one's acquaintances in the network. In social network parlance, people with whom one is close to are referred to as strong ties (high density), while acquaintances are weak ties (low density). Since one's acquaintances (weak ties) would have his or her close ties, it can be assumed that weak ties are a bridge to an acquaintance's close ties. While weak ties may connect individuals who are akin, however, they are more likely than strong ties in linking groups that are different and possess novel information (Granovetter, 1973). Therefore, while strong ties are more significant than weak ties in delivering support, weak ties play an important role in delivering information. These implications will be further discussed in the context of kidney transplantation in a subsequent section.



Just like the degree of social integration does not imply corresponding support functions, social network size is not a clear indication of potential social support (House et al., 1985; Schaefer et al., 1981; Tracy & Whittaker, 1990). A review by Cohen and Wills (1985) indicated that several studies have found a low correlation of .20 to .30 between network size and network function. However, the proportion and number of friends in one's social network have higher predictive value regarding potential and actual social support (Tracy & Whittaker, 1990). In other words, an individual with more family and friends in the social network will have more social support than one whose network comprises mainly of acquaintances.

#### **2.4.5 Social Support**

One function served by social network is the provision of social support, this is one mechanism by which social network can influence health (Berkman et al., 2000; Smith & Christakis, 2008; Uchino et al., 1996). Social support arrives in various forms and its main types are 1) emotional support—referring to intimacy and attachment, 2) instrumental or tangible support which considers direct help or services, 3) informational support (aka appraisal support and cognitive guidance) which is help with information, advice, feedback and guidance that facilitates perception of problematic situations and problem solving, and 4) esteem support which conveys a person's worth and acceptance (S. Cohen & Wills, 1985; House, Landis, et al., 1988; Schaefer et al., 1981). Theoretically these categories of social support are independently defined although in reality they often overlap (S. Cohen & Wills, 1985). In fact emotional, informational and appraisal support are usually intertwined (Berkman et al., 2000). As an example, when a transplant recipient shares the transplant experience with another patient who is contemplating kidney transplantation, the latter is collectively receiving informational, appraisal and emotional support (in the form of empathy from another patient). Each type of support influences health

and psychological outcomes differently since the effects of each type of support may not be replicable by the other types of social support. For instance, providing only emotional support to a low income, single mother fatigued from holding two jobs and raising two young children may make her feel emotionally supported. However, such help does not contribute to her coping with the financial distress and physical burden of her circumstances. Hence it delivers different psychological and health effects than if she was given tangible support to cope with the demands of her stressful life situation.

Social support is measured in various ways such as perceived, actual or the discrepancy between perceived support and actual social support (Reblin & Uchino, 2008). Perceived social support refers to the individual's perception of the supportive value of the interaction (Schaefer et al., 1981) or the belief that resources are available for him or her if they are needed (Wills & Shinar, 2000). Higher levels of perceived social support are associated with enhanced health outcomes (House, Landis, et al., 1988). Actual social support refers to the actual receipt of social support and this information is often verified by asking the providers of social support (Reblin & Uchino, 2008). Some scholars believe that perceived social support is a more accurate reflection of an individual's support system availability because actual social support is tied to need. That is, a person not receiving actual social support is not necessarily an indication of having a weak or unsupportive social network but it could be related to the person having adequate resources to cope and not needing additional support (Harknett & Hartnett, 2011). From this perspective, actual social support can be susceptible to ambiguity when measured.

#### **2.4.6 Main or Buffering Effects**

While it is clear that social support is positively associated with health, it is less clear when social support confers health benefits. Scientists attempt to theorize whether social support has

main or buffering effects on health (Cohen & Wills, 1985; House et al., 1988; Cohen & Syme, 2000, Cohen, 2004). The stress buffering model asserts social support does not offer beneficial health effects in non-stressful situations and that is it only when individuals are confronted with stress that the presence of social support has protective effects on health. The alternative perspective proposes that social support has main effects, that is, the presence of social support inherently enhances well-being, irrespective if an individual is experiencing life stress (Cohen & Wills, 1985; House et al, 1988; Berman et al., 2000). Durkheim's (1954) pioneering work demonstrating the reduced suicide risk of socially integrated people compared to those who were socially isolated is an example of the main effects of social support (House, Landis, et al., 1988; House, Umberson, et al., 1988). Being socially integrated provides a person with a sense of self-worth and positive experience, potentially mitigating deleterious effects of negative life events and thereby promoting health (S. Cohen, 2004; S. Cohen & Syme, 1985; S. Cohen & Wills, 1985). Instead of asserting that social support has either main or buffering effects, updated scholarship has evidenced support for both (review by S. Cohen & Wills, 1985).

#### **2.4.7 Social Support Mechanisms or Pathways**

The mechanism and processes by which social support promotes health is not fully understood and various theories have been posited (Cohen, 1988; Franks et al., 1992; Patel et al., 2005). Berkman, Glass, Brissette and Seaman (2000) conceptualized social networks impact on health that considers the cascading impact of upstream, macro-level social-structural conditions (such as culture, socio-economic factors, politics and social change) on mezzo-level social network (such as network size, density, frequency of contacts, homogeneity) and on downstream factors of micro-level behavioral mechanisms and pathways. The social network construct provides a platform for 1) social support, 2) social influence, 3) social engagement, and 4) access to

material goods and resources. These behavioral mechanisms trigger psycho-biological (e.g. immunological response), psychosocial (e.g. enhanced coping, sense of mastery) and health behavior (e.g. treatment adherence, engagement in healthy lifestyle) pathways within the individual to affect health.

Cohen (1988) theorized different pathways to explain the influence of social support on health and this includes 1) a generic model for the main effect pathway, 2) a stress-centered model for the stress buffering pathway, and 3) a psychosocial model that considers both the main effect and buffering effect pathways. Since earlier discussion documents contemporaneous presentation of both effects (review by S. Cohen & Wills, 1985), only the third model will be mentioned here and is illustrated in Table 1 below. In both models, the following pathways are noted: 1) information-based models, 2) identity and self-esteem models, 3) social influence models, and 4) tangible-resource models (S. Cohen, 1988).

Table 1. *Psychosocial pathways for main and stress-buffering effects of social support on health*

Psychological pathways of social support on disease	Main effect model	Stress-buffering model
Information-based models	A wide social network leads to more information sources and consequently, better access to appropriate information that aids in coping. Information has the potential to influence health-related behavior or link a person to avenues for support or help.	Information received from one's social network can potentially lead to a reduction in the stress appraisal of a situation. Even the perception of availability of information support, without the receipt of actual support, may reduce stress appraisal, and this has a potential in reducing one's engagement in unhealthy health-related behavior.

Table 1 (Continued)

Psychological pathways of social support on disease	Main effect model	Stress-buffering model
Identity and self-esteem models	Increased social support can boost one's self-esteem and self-identity in various ways, and such favorable self-appraisals lead to more positive health outcomes.	An enhanced self-esteem and self-identity can result from knowing that one has a social support network to rely on for help, or actually relying on the network for help. Such positive effect can increase one's motivation to engage in positive health behavior while avoiding negative ones.

Table 1 (Continued)

Psychological pathways of social support on disease	Main effect model	Stress-buffering model
Social influence models	<p>One's social network has the potential of influencing one's health-related behavior through social norms and pressure exerted by the network. Hence health outcomes can be positive or negative contingent on the nature of influence exerted by the network.</p>	<p>The social influence and pressure received from one's social network can cause one to conform to expected social norms. Where such normative behavior is health-enhancing, social support then leads to better health outcomes. Conversely, if one's social network engages in maladaptive health-related behavior, then, greater risk of stress-related disease can result.</p>

Table 1 (Continued)

Psychological pathways of social support on disease	Main effect model	Stress-buffering model
Tangible-resource models	Membership in a social network can lead the individual to becoming connected with sources of tangible aid.	The actual or belief in provision of aid by one's social network can reduce stressful events as being appraised as stressful or threatening, hence leading to better affective response and better health outcomes.

#### 2.4.8 Negative Aspects of Social Relationships

It must be clarified that although social relationships have beneficial health effects, this is not always the case. Social relationships can be a form of stress because of expectations, roles and responsibilities that accompany some relationships. Besides, efforts are required to maintain social ties (Schaefer et al., 1981; Scott, Martin, Stone, & Brashers, 2011). Social relationships exert social control and social regulation on individuals and these can be stressful. Social control can be exerted through direct means by facilitating or imposing health-enhancing behavior. An example of this would be when a caregiver controls and limits the amount of fluid a dialysis-dependent family member can consume in a day so as to enforce treatment adherence. Indirect social control occurs by expecting conformity to social norms, and acting from a sense of



responsibility towards others is one such example. As an illustration, a mother may feel compelled to donate a kidney to her child because she feels it is her moral and parental obligation to emancipate the child from the throes of dialysis. Social regulation is the “constraint of an individual’s behavior by another individual or societal proscription” (House, Umberson, et al., 1988, p.306). Conforming to social norms is an example of social regulation. If conforming to social norm implies engaging in unhealthy behavior, for example when a teenager is pressured to smoke cigarettes in order to be accepted by his peer group, or if conforming to social norms creates stress within the individual, then social relationships in these contexts are stressful instead of supportive.

Close personal relationships that are characteristically hurtful or stressful have been known to cause persistent immune dysregulation (Kiecolt-Glaser, McGuire, Robles, & Glaser, 2002; Uchino et al., 1996) and those that are negative or conflictive can be deleterious to health (House, Landis, et al., 1988; Lincoln, 2000; Uchino, 2009). It is widely known that families can be a source of support and stress, just as marital relationships that are less positive and higher in conflict and hostility can have detrimental health effects and alter illness perceptions (review by Kimmel, 2000b). An early study found a significant association between marital strain and psychological distress among dialysis patients (Chowanec & Binik, 1989). A study comparing African American ESRD patients living in simple households (that is, living alone or with their spouse) versus those in complex households (defined as living with spouse/partner and/or others) found that those who were in complex households had higher mortality risks. Further, women in complex households face double the risk for shortened survival compared to those in simple households (Turner-Musa et al., 1999).

Besides delivering social support, social networks are conduits for the spread of health information, disease, cultural norms, health behavior and attitude —transmitting these whether in favorable or undesirable forms (S. Cohen, 1988, 2004; House, Landis, et al., 1988). Therefore if an individual's social network contains elements that are negative to health beliefs and behavior, that individual is more likely to be influenced accordingly. For example, the cultural and religious beliefs of African Americans disinclining them towards organ transplantations (Alexander & Sehgal, 1998; Held, Pauly, Bovbjerg, Newmann, & Salvatierra Jr, 1988; Myaskovsky et al., 2012), or their higher likelihood of having inaccurate KT knowledge compared to Caucasians (Browne, 2008; Waterman et al., 2013) are plausibly spread through their social networks (Arthur, 2002).

#### **2.4.9 Social Support, Social Network and Demographic Factors**

Demographic factors such as gender, age, marital status and socio-economic status can also affect the amount of social support a person enjoys (Ajrouch et al., 2005; Cukor et al., 2007; Turner & Marino, 1994). There are divergent views if social support increases or declines with age (Turner & Marino, 1994), although it appears that evidence tends to support the observations that network sizes and contacts shrink with age (Ajrouch, Antonucci, & Janevic, 2001; Ajrouch et al., 2005). Gender difference exists in the receipt and giving of social support. Kimmel et al. (2003) determined from their hemodialysis study sample that women perceived more social support than men. Women reportedly provide more social support compared to men, and being married benefits them less than men (House, 1987; Turner & Marino, 1994). However, Turner and Marino (1994) observed that despite receiving more social support than men, women had correspondingly more psychological distress. Most studies demonstrate that social relationships are a stronger influence on men's health and mortality than women's, and that both genders

benefit more from social relationships with women than with men (House, Landis, et al., 1988; Uchino et al., 1996). Social support also differs across race, with at least one study among hemodialysis patients documenting lower levels of instrumental social support among African American patients compared to whites, and this has negative implication on the completion of KT evaluation (Clark et al., 2008). However another study on kidney, liver and pancreas recipients found that African Americans received significantly more social support and for a longer duration than whites, and that the levels of social support did not vary significantly across income groups. (Cetingok et al., 2008). Kimmel and colleagues (2003) also found in their study that African Americans reported higher levels of social support than their white counterparts. Generally existing data suggest that individuals from lower SES group suffer from a poorer quality of social relationships and support (Ajrouch et al., 2005; House, 1987; Turner & Marino, 1994). Utilizing data from the national Fragile Families and Child Wellbeing Study involving 12,140 respondents, the authors concluded that mothers with personal disadvantages—including poverty and health problems, among other factors—had lower levels of perceived social support, particularly instrumental support. One explanation is that because of the tendency of homophily in social network, mothers who are poor would have social networks that consist primarily of poor people who are therefore unable to offer much help (Harknett & Hartnett, 2011).

#### **2.4.10 Social Networks and KT**

Scholars have recommended the use of network analysis in understanding health and illness behavior, especially where access to information is important (Arthur, 2002; House, Landis, et al., 1988). The examination of social networks as a source of potential support and its influence on completion of KT evaluation has been proposed because it is known that patients receive information on ESRD treatment modality not just from their health care providers but also from

their social network (Arthur, 2002; K. Ladin & Hanto, 2010; Weng et al., 2005). For example, knowing someone in one's social network who had a failed transplant diminishes one's interest in pursuing kidney transplantation (Gordon, 2001; Holley, McCauley, Doherty, Stackiewicz, & Johnson, 1996). Targeting social networks in order to increase its positive and reduce its negative influence concerning KT knowledge, attitudes, access and preference has been identified as a means to address disparities in organ transplantation (K. Ladin & Hanto, 2010). However this area has received limited attention (Clark et al., 2008). Arthur (2002) is among the handful advocating for the examination of an individual's social network in influencing decisions regarding kidney transplantation because she believes that kidney transplantation is a social phenomenon contingent on access to information support through one's social network. In adopting Granovetter's (1973) strength of weak ties theory where weak ties function as links to social networks diverse from one's strong ties, Arthur (2002) postulates that existing evidence on African Americans' proclivity to receive social support from strong ties—which tend to be homogenous—restricts their access to diverse and complex information about kidney transplantation that is more likely to be found among weak ties. This cultural variation in social support networks is believed to lower African Americans' pursuit of kidney transplantation when compared to whites. Ladin and Hanto (2010) hypothesize along a similar vein that social network influences access to KT information. For example, a patient whose social network is knowledgeable about kidney transplantation benefits from the informal KT education received from one's network. Evidence for this hypothesis is supported by various studies involving different ethnic groups (Exley, Sim, Reid, Jackson, & West, 1996; Randhawa, 2005).

To corroborate the assertion that social networks influence KT knowledge, Browne (2008) conducted a study involving 228 African American patients between the ages of 18 and

65 who were receiving hemodialysis at one of the five dialysis units in the Chicago area (Browne, 2008). This study measured the content of the social network, not the structure of the social network. That is, it examined the presence of KT information or knowledge among the patients' social networks and not its density or strength because it is posited that it is the content, not the strength of the social network that matters in influencing decisions for kidney transplantation. Indeed the study outcomes evidenced that having informational support was significantly related to participants possessing accurate information about KT, and patients who knew of a kidney recipient or donor were also more likely to have information about KT. Therefore as long as a patient's social network consists of someone with KT information, the patient benefits from this informational support by being enabled in navigating the kidney transplant pathway, hence resulting in a higher likelihood of being evaluated at a transplant center. This advantage remains even if the patient does not have a strong social network.

The benefit of utilizing social networks in increasing living donor kidney transplantation (LDKT) was demonstrated in an un-randomized control trial involving 180 African American patients accepted for treatment in a southeastern US transplant center (J. R. Rodrigue et al., 2012). The patients were enrolled in one of the three conditions: 1) clinic-based individual transplant counselling and education, 2) clinic-based group transplant counselling and education involving three to five patients and their accompanying persons, and 3) home-based group transplant education program ("House Calls"). KT information and education delivered at a transplant center can directly reach patients and any of their accompanying persons only. Spreading such resource with the aim of expanding the reach in finding a potential living donor in the patients' social networks becomes contingent on the patients' ability in disseminating such information to their networks. On the other hand, if KT education is conducted in patients'

homes where patients are encouraged to invite as many people in their networks (for example, immediate and extended family members, colleagues, close friends, church members) to attend, this increases the outreach in patients' social networks with the potential of increasing the probability of finding a living donor within the networks. The results of the study supported the rationale that targeting patients' social networks directly through home-based LDRT education would increase LDRT interest and actualization. The study found that those in the House Calls group had a higher number on LDRT enquiries, evaluations and procedures. Such similar outcomes were documented in another study whereby 132 patients in a university transplant center were randomized to receive either clinic-based or clinic-based and home-based LDRT education (J. Rodrigue, Cornell, Lin, Kaplan, & Howard, 2007).

The above discussions provide convincing evidence on how social networks can influence patients' behavior along the kidney transplantation process. Additionally, it is known that social networks that provide little or no social support is a significant psychosocial risk factor for poor post-transplant outcomes (Jowsey, Taylor, Schneekloth, & Clark, 2001), whereas a supportive social network improves the ESRD patient's chance of producing a living kidney donor within the network (Cass et al., 2003). Differences in social networks along the demographic dimension (for example, age, gender, race and income) can influence patients' personal network characteristics and access to treatment information from their health care providers (Cass et al., 2003; K. Ladin & Hanto, 2010; Turner & Marino, 1994). At least one study demonstrated that patients from high SES group are more likely perceived by physicians as having a supportive social network—hence are believed to be better KT candidates—leading to them being more likely to be referred for kidney transplantation than compared with those from low SES group (Cass et al., 2003).

### **2.4.11 Social Support and KT**

As earlier mentioned, social support facilitates progress in and completion of KT evaluations (Cass et al., 2003; Kazley et al., 2012; Scandling, 2005; Steinman et al., 2001). Transplant programs utilizing social support groups in aiding patients through the transplantation process demonstrates the belief among professionals in the importance of social support (M. Dew et al., 2002). Social support required for patients undergoing transplant evaluation can range from instrumental (such as transportation to transplant centers for evaluation or errands), to informational (such as comprehending transplant-related information or communication with healthcare providers) to emotional (Scandling, 2005). Even caregivers of transplant candidates have been identified as requiring social support to aid in coping with the pre-transplant, peri-operative and post-transplant stages (Skotzko, et al., 2001). Unfortunately social support is under-studied in those who are considering or awaiting a KT (Scott D Cohen et al., 2007; Patel, Peterson, & Kimmel, 2005), despite the emphasis on social support as a requirement and critical consideration for kidney as well as other solid organ transplants (Bunnapradist & Danovitch, 2007; Mehra et al., 2006; Olbrisch, Benedict, Ashe, & Levenson, 2002; Pham et al., 2010; Rudis, Rudis, Lupo, Safady, & Bonne, 2000). Also, there is a lack of consistency on how social support is to be evidenced by patients, resulting in possible reduction of fairness in transplantation listing (K. Ladin & Hanto, 2010). Nonetheless the availability of social support is regarded as integral for patients' well-being and it is indicated among the criteria for KT by the Clinical Practice Committee of the American Society of Transplantation (Steinman et al., 2001), and in the recently developed Stanford Integrated Psychosocial Assessment for Transplantation (SIPAT) (Maldonado et al., 2012). Many transplant programs regard a lack of social support as a contraindication for transplant listing (Collins & Labott, 2007).

Besides a KT candidacy criterion, social support availability is positively correlated with utilization of medical services, including KT evaluation (Kazley et al., 2012; Patel et al., 2005). Thus it can be postulated that ESRD patients with more social support are more likely to inquire about and engage in the KT evaluation process; and there is evidence to support this. Clark and colleagues (2008) examined 742 hemodialysis patients in four regional networks nine months after their dialysis initiation and found that patients with high levels of instrumental social support were more likely than those with low instrumental support to complete KT evaluations (46% v. 25%). The authors concluded that the presence of instrumental social support resulted in patients having more time and energy to adhere with KT evaluation appointments, hence a higher chance of completing the evaluations (Clark et al., 2008). A single-center study of 83 patients who were referred for KT evaluation but who did not complete it found that misinformation on KT criteria and process, and a lack of transportation means or affordability to attend KT evaluations partly attributed to attrition in KT evaluations (Kazley et al., 2012). These studies highlight that the presence of social support can help patients in accessing and utilizing medical services.

The pre-transplant phase is known to be a stressful period for patients (Levenson & Olbrisch, 1987; Rainer et al., 2010). They have to deal with the idea of undergoing a major surgery, the uncertainty regarding the availability of a donor, the post-transplant need for lifelong immuno-suppressants, potential organ rejection or failure, as well as dealing with anxiety and depression commonly experienced by ESRD patients (Sensky, 1993). Some patients awaiting a transplant have described their experience as living in hope, uncertainty and having their life placed on hold (A. Moran, Scott, & Darbyshire, 2011). Patients awaiting the availability of a deceased organ donor may also experience intrusive thoughts such as thoughts about the



circumstances that could result in deceased kidney donation opportunities, negative feelings towards other KT recipients for having preceded them in receiving a KT, and fear of death during the transplant surgery (Sensky, 1993). At least one study found that family support—defined as an environment that allows family expressiveness of feelings—lowered the levels of intrusive thoughts, anxiety and depression among the 75 KT candidates examined (P. J. Moran, Christensen, & Ehlers, 1999). In other words, a supportive family environment that encourages the expression of stressful thoughts and feelings regarding KT helps patients cope with this stressful period.

The benefits of social support extend beyond the pre-transplant to the post-transplant phase in aiding coping and survival (Christensen & Ehlers, 2002), and contributing to patients' quality of life (Rainer et al., 2010). Better health status is associated with more social support in KT recipients (J. Rosenberger et al., 2006). On the other hand, a lack of social support is partially accountable for post-transplant psychological disorders (Rainer et al., 2010). In a study of 50 kidney transplant recipients where almost two-thirds were African Americans, the authors found that a higher level of social support was among the factors associated with better QOL (Shah et al., 2006). Another study found that social support buffered the impact of high level illness-related physical debilitations on anxiety and depression among 57 kidney transplant recipients (Christensen, Turner, Slaughter, & Holman Jr, 1989). Here social support was measured on the domains of family cohesion (the degree of supportiveness among family members), family expressiveness (the degree to which family members can openly act or express their feelings) and family conflict (the degree to which anger and conflict characterizes the family) and the participants were classified as having high or low illness-related physical dysfunction. Among participants with high illness-related physical dysfunction, those who had

low levels of perceived family support were significantly more likely to have depressive symptoms and anxiety than those from a supportive family environment. However family support had no influence on depressive symptoms and anxiety among those with low illness-related physical dysfunction.

#### **2.4.12 Social Support and Dialysis**

The USRDS (2013) reported that only 3.3% of transplanted cases in 2011 were pre-emptive transplants, implying that the majority of patients undergoing KT evaluations are already dialysis-dependent. Therefore most patients undergoing KT evaluations have to deal with the stress of KT evaluations in addition to the stress of dialysis treatment. A discussion on social support and dialysis will increase our understanding on the role of social support in aiding this population group. Also, by situating kidney transplantation process as a point along the ESRD treatment trajectory, drawing on social support and dialysis research will buttress the argument that social support deserves greater examination among ESRD patients presenting for KT evaluations.

Social support has been credited for abating the impact of depression—the most prevalent psychological disorder in the ESRD population—in ESRD patients (Kimmel, et al., 1995). A Chinese study on peritoneal dialysis patients corroborated prevailing evidence that social support reduces depressive and anxiety symptoms (Ye et al., 2008). The literature on social support and treatment adherence among dialysis patients is, however, met with mixed results. For example, one study found that dialysis-dependent women with higher levels of perceived spousal support was associated with better treatment compliance and survival (S. D. Cohen, et al., 2007), while another study concluded that social support did not affect treatment adherence (Cummings, Becker, Kirscht, & Levin, 1982).

Kimmel et al. (2003) confirmed that the presence of social support contributed to better quality of life and satisfaction of life among 165 hemodialysis patients. A larger study involving 949 dialysis patients from 77 facilities corroborated the contribution of social support to better quality of life, besides lowering patients' hospitalization rate and increasing their satisfaction with care (L. C. Plantinga et al., 2010). A major study involving 32,332 hemodialysis patients enrolled in the Dialysis Outcomes and Practice Patterns Study (DOPPS) in 12 countries from 1996 to 2008 proved that poor social support was strongly associated with reduced treatment adherence, reduced QOL and a higher mortality rate (Untas et al., 2011). In addition to contributing to a better quality of life and abating the impact psychological impact of ESRD, social support is credited for improving dialysis survival and reducing mortality risk (Christensen, Wiebe, Smith, & Turner, 1994; Kimmel et al., 1998; McClellan, Stanwyck, & Anson, 1993; Thong et al., 2007).

#### **2.4.13 Summary**

The rich reservoir of scholarship attests to the health-enhancing benefits of social support, and has advanced our understanding on social relationships and health. At the same time equivocal findings complicate interpretations of the results, which are partly attributable to a lack of consistent definition of social support and varying measurements of social support in this sphere of scholarly work (S. Cohen & Syme, 1985; House, 1987; House et al., 1985; Lincoln, 2000; Reblin & Uchino, 2008). Further, design constraints limit conclusions on causality—because most work relied on cross-sectional design—or produce spurious effects (Scott D Cohen et al., 2007; House, Umberson, et al., 1988; Reblin & Uchino, 2008). It is unclear for example, if fewer social relationships lead to poorer health outcomes, or that people who are ill have difficulty maintaining social relationships (House, Landis, et al., 1988). Few studies measured

the link between social structures and its delivery of social function, such as the conveyance of social support (House, 1987; Reblin & Uchino, 2008). Distinguishing between the existence and quantity of social relationships and the actual content of social support these relationships provide is important in elucidating the impact of social support on health (House, Umberson, et al., 1988). The use of self-report measures on social support was prevalent (House, Landis, et al., 1988), and many social support studies relied on small sample size and targeted population groups that limit generalizability (House, 1987; Reblin & Uchino, 2008). Differences in psychosocial evaluation practices also contributed to the varying study outcomes (Skotzko, Stowe, Wright, Kendall, & Dew, 2001). Further, difficulties exist in controlling for extraneous factors such as the effects of ageing on illness deterioration, illness severity and how it may reduce the influence of social support (Callaghan & Morrissey, 1993). Isolating the influence of social support on health is insurmountable because contemporaneous factors like lifespan development, individual personality and family interactions are among other confounding variables (Franks, Campbell, & Shields, 1992; House, 1987).

Methodological complexity and a dearth of data also complicates research on social network and health, thus limiting the number of such studies in comparison to studies on social support and health (Smith & Christakis, 2008). Social network analysis is complex and involves prohibitive costs. Consequently studies that measured social networks limited their analysis to individual-level measures of social contact, i.e. self-reports on the number of social contact and closeness and did not expand to engaging in complex social network analysis that would have to include the links between the social ties (Smith & Christakis, 2008; Tracy & Whittaker, 1990). Even if social network was measured, there was no agreement on what network size is considered adequate (Tracy & Whittaker, 1990).

Notwithstanding the constraints and divergent conclusions apparent in this field of study, it is indisputable that social support promotes health and illness coping, and ameliorates disease burden, functional debilitations, and psychological distress concomitant with ESRD (Christensen et al., 1989; Devins et al., 1983; Devins et al., 1993; Gerald M Devins et al., 1990; Kimmel, 2000b; Kimmel et al., 1995). There is substantial evidence of social support facilitating progress in and completion of KT evaluations (Cass et al., 2003; Kazley et al., 2012; Scandling, 2005; Steinman et al., 2001). Collectively, the scholarship corroborates how social support has helped recipients of various organ transplant types cope with the uncertainty that characterize both the pre and post-transplant phases, in addition to contributing to the quality of life (Christensen & Ehlers, 2002; M. A. Dew et al., 2005; Mary A Dew et al., 1994; Galbraith & Hathaway, 2004; Rainer et al., 2010; E. M. Rosenberger, Dew, Crone, & DiMartini, 2012; J. Rosenberger et al., 2006; Scott et al., 2011; Shah et al., 2006). Social network characteristics are known to influence KT knowledge, attitudes and beliefs, and these have a role in influencing the completion of the KT evaluation (Browne, 2008; Cass et al., 2003; K. Ladin & Hanto, 2010; Turner & Marino, 1994; Waterman et al., 2013). The variations in findings should be perceived beyond their conceptual and methodological limitations, and regarded as the dynamic nature of social support, which affects and is affected by a gamut of factors ranging from the individual, familial to the societal level, and by different disease types and trajectories. Because social support is a multi-factorial construct, arriving at a universal definition of social support that includes all or most of its dimensions remains difficult (Lincoln, 2000). However this should not dampen efforts in further research, especially in the area of KT evaluation that remains underdeveloped. The proposed study examining the influence of social support, illness burden and the associations between them in the completion of KT evaluation, is a first in the field. Results

from this innovative study will elucidate our understanding on how these factors affect the completion of KT evaluation. The results, in turn, can guide the development of intervention strategies to help aid more ESRD patients, particularly those who are disadvantaged, in successfully completing the KT evaluation, thereby reducing disparities in access to kidney transplantation.

## 2.5 THEORETICAL FRAMEWORK

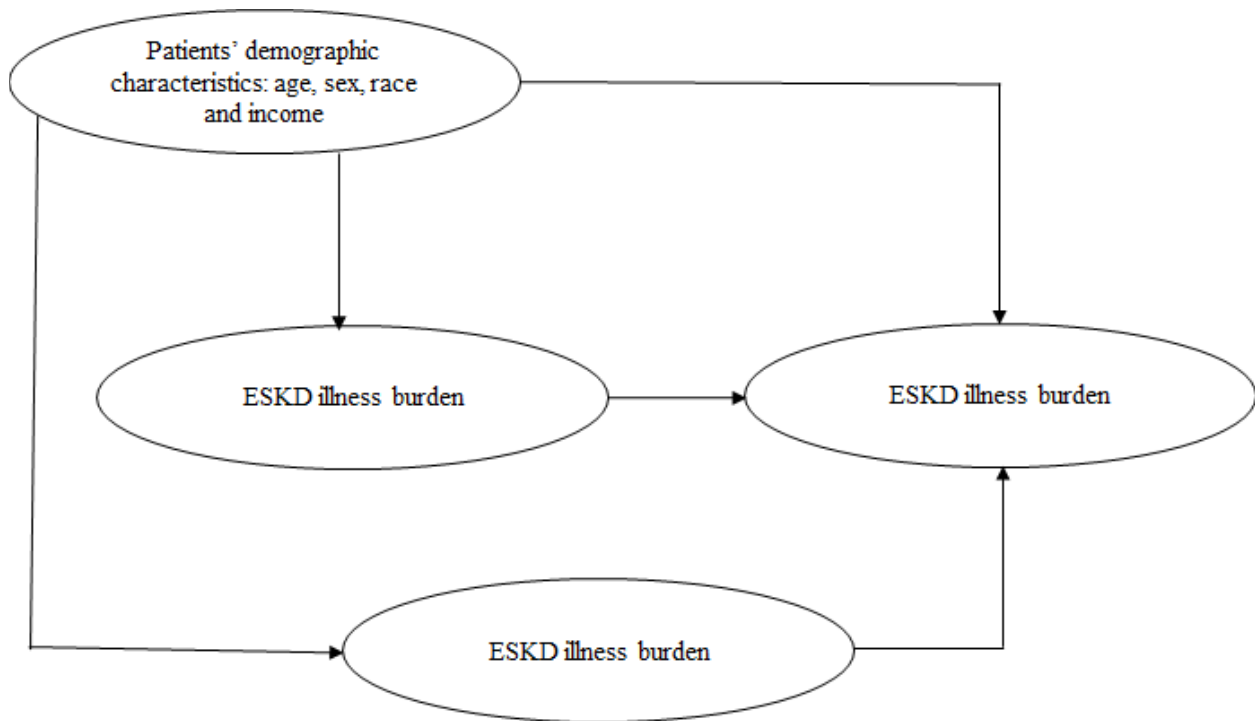


Figure 1. Conceptual Model: Relationship between Social Support, ESRD Illness Burden and Time Taken to Complete Kidney Transplant Evaluation.

The literature reviewed informs the rationale behind the proposed model (Figure 1) on how social support, illness burden and demographic factors interact and influence the time taken to complete KT evaluation. The literature provides convincing evidence that social support affects time taken to complete KT evaluation (Arthur, 2002; Cass, et al., 2003; K. Ladin & Hanto, 2010; Rodrigue, et al., 2008; Scandling, 2005; Steinman, et al., 2001; Sullivan, et al., 2012; Weng, et al., 2005).

Social support definitions vary across studies. In the proposed study, social support will be examined from the structural and functional aspects consisting of social network size and perceived social support. No previous work has examined how illness burden may affect the time taken to complete KT evaluation. But it would stand to argue that such a variable is important to consider because others have found that illness burden can interfere with life activities (Devins, et al., 1993; Gerald M Devins, et al., 1990; Kimmel, 2000; Kring & Crane, 2009), and such interference disrupts patients' participation in KT evaluation and impedes on their completion of KT evaluation. Thus it can be posited that illness burden affects time taken to complete KT evaluation. Built on the premise that social support can ameliorate illness burden (Kimmel, 2000; Kimmel, et al., 1998; Kimmel, et al., 1995), the model considers how social support buffers ESRD illness burden and influence KT evaluation completion time. The conceptual model also considers and controls for demographic factors such as age, gender, race and income, since these are known to have associations with social support (Ajrouch, et al., 2005; Cetingok, et al., 2008; Clark, et al., 2008; Cukor, et al., 2007; House, Landis, et al., 1988; Turner & Marino, 1994), illness burden (Cukor, et al., 2007), and time taken to complete KT evaluation (Browne, 2008; Held, et al., 1988; Schaeffner, et al., 2008; Waterman, et al., 2013).

The conceptual model is supported by stress and coping theory and social support theory. Lazarus and Folkman's (1984) transactional stress-coping theory has been widely accepted in explaining coping with chronic illnesses (Schreurs & de Ridder, 1997). According to Lazarus and Folkman (1984), when confronted with a potentially stressful situation, the event presents as stressful if an individual appraises it as such, or when the individual appraises the demands of the situation as exceeding his/her coping resources. The appraisal of the stressor is referred to as the primary appraisal, which also considers what is at stake. The secondary appraisal is activated when the individual appraises his/her ability, availability of resources and effectiveness of a probable coping option in dealing with the stressful situation. These cognitive appraisals in turn influence the coping response. If the appraisal indicates that something can be done to ameliorate the situation, problem-focused coping is initiated. If the appraisal indicates that nothing can be done, emotion-focused coping is invoked. In the problem-focused coping, the individual takes action to alter the stressful situation, while in the emotion-focused coping, the individual modulates his/her emotional response to the stressor to cope (Lazarus & Folkman, 1984). Succinctly, coping responses are a result of an individual's appraisal of a stressor and the belief in one's availability of resources to cope with the stressful event. There are other factors that shape the appraisals of stressful events but they are not within the scope of focus for this study and will not be discussed.

According to Lazarus and Folkman (1984), stress appraisals include harm/loss, threat and challenge. Physical illness is a stressful life event. This is particularly so in ESRD because patients experience loss of health and normalcy, symptom and illness burden, in addition to dealing with the chronicity and treatment demands of ESRD that negatively affect various facets of life, and the threat of a shortened lifespan (Hagren et al., 2001; Jassal, Schaubel, & Fenton,



2005; Kimmel, 2001; Kring & Crane, 2009; Murtagh et al., 2007; Timmers et al., 2008). Nonetheless, like in other potentially stressful situations, the degree to which ESRD is stressful depends on the patients' perception of the illness, and this perception in turn affects the ESRD illness impact or illness burden (Devins, 1994; Kimmel et al., 1995; Timmers et al., 2008). Based on the transactional stress-coping theory, a patient's perception of ESRD illness burden (primary appraisal) will lead to him/her to seek ways to cope with the illness (secondary appraisal); and one problem-focused alternative is for the patient to mobilize social support. Social support is an identified coping resource in the research on stress and coping (Lazarus and Folkman, 1984). In this context, ESRD illness burden is the operationalization of the stress, whereas social support is the coping resource to deal with the ESRD illness burden, as well as with the multi-step demands of KT evaluation.

The perspective that social support is a coping resource is consistent with the presented evidence that the presence of social support buffers stressful life events, and this includes ESRD illness burden (S. Cohen & Wills, 1985; Scott D Cohen et al., 2007; Thoits, 1982). According to social support theory, the belief that one's social network can be the link to coping resources has been documented in reducing one's negative perception of stressors, and/or increase one's sense of coping, thereby reframing the situation as non-stressful and consequentially offer health benefits to the person (S. Cohen, 1988, 2004; S. Cohen & Syme, 1985; S. Cohen & Wills, 1985; Reblin & Uchino, 2008). Additionally the actual receipt of social support buffers illness impact in that affected individuals are enabled through resources to cope with the illness. Further, a person's perception of the availability and accessibility of support have been found to influence his or her utilization of social network resource (Lewis et al., 2000). Thus, a person who perceives his/her social network as supportive will more likely seek out the network for support,

resulting in a higher likelihood of the person receiving actual aid and coping. However, in order that social support can buffer stress, the type of support provided must be appropriate to the nature of needs of the person requiring the support (S. Cohen & Wills, 1985). As an example, if an individual requires emotional support but is offered informational support instead, then the informational support does little in abating the level of stress. In the context KT evaluation, examples of potential support required by patients may include provision of KT information, transportation to transplant clinic, and counseling services to help patients cope with the stress of ESRD and KT evaluations.

Social support theory also posits that higher levels of social support lead to better health outcomes (House, Landis, et al., 1988). Similarly, a more extensive social network provides for multiple sources of information that potentially results in greater influence in health behavior and outcomes than compared to a limited social network (S. Cohen, 2004). And although the size of one's social network affects the level of social support a person receives, these two factors do not necessarily or always correspond with one another (S. Cohen & Wills, 1985; House, et al., 1985; Schaefer, et al., 1981). Nonetheless a person's perceptions of the availability and accessibility of support have been found to influence his or her utilization of social network resource (Lewis et al., 2000). Thus, a person who perceives his/her social network as supportive will more likely seek out the network for support, resulting in a higher likelihood of the person receiving actual aid and coping. However, the exact mechanisms and processes by which social support affects health is not yet fully understood (refer to pp. 21-23 "Social support mechanisms or pathways") (Berkman, et al., 2000; S. Cohen, 1988, 2004; S. Cohen & Wills, 1985; Patel, et al., 2005).

## **3.0 METHODS**

### **3.1 STUDY DESIGN**

This study utilized secondary data analysis from a prospective cohort study at the Starzl Transplant Institute, University of Pittsburgh Medical Center (UPMC) led by Dr. Larissa Myaskovsky. Before receiving a kidney transplant (KT), patients must complete a KT evaluation (also known as a pre-transplant work-up), to assess medical and psychosocial eligibility. At the conclusion of the initial transplant clinic appointment at the Starzl Transplant Institute, the patient is given a list of all the tests that must be completed for the KT evaluation (e.g., bloodwork, cardiac catheterization, dental clearance, etc.). Upon completion of all necessary testing for KT evaluation, the patient's medical record and test results are presented to the transplant team. Based on these findings, the transplant team determines whether to accept or reject the patient for KT based on prevailing medical and psychosocial recommendations and/or criteria (Bunnapradist & Danovitch, 2007). For those who are accepted for KT, they are placed on a national KT wait list operated by the United Network for Organ Sharing (UNOS). The patients are tracked by the transplant team using an electronic database containing all health-related information and the most up-to-date patient contact information.

The parent study aims were to identify culturally-related and psychosocial factors associated with race disparities in transplant decision-making, acceptance for transplant, type of transplant

received (living versus deceased donor KT), and early post-transplant health outcomes in ESRD patients who presented for KT evaluation. The study was conducted in partnership with the Survey Research Program (SRP) at the University of Pittsburgh's Center for Social and Urban Research (UCSUR) to develop the telephone interview, program the computer-assisted telephone interview (CATI) system, develop and program the interview tracking system, train interviewers, and produce detailed progress reports. The SRP has extensive experience conducting telephone interviews with patients from different population groups using CATI system. The University of Pittsburgh Institutional Review Board (IRB) approved the conduct of this research. All participants provided written informed consent before participating in the project.

### **3.2 PROCEDURES FOR SAMPLING AND DATA COLLECTION**

Patients presenting at the Starzl Transplant Institute who were 18 years or older, English-speaking, and who had not previously received a KT were eligible for the study. Previously transplanted patients were excluded because their prior experience could affect their current transplant decision making (Holley et al., 1996).

Patients who agreed to participate in the study were measured at three time points. The first time point (Time 1) occurred after the patient's first visit to the transplant clinic when pre-transplant workup commenced. The second time point (Time 2) occurred after the completion of the KT evaluation. The third time point (Time 3) was conducted only for those who received a KT, and occurred approximately six months post-transplant. For the aims and hypotheses of the current secondary-data analytic study, only data at Time 1 and Time 2 were utilized because the focus was not on post-transplant health outcomes.

During the course of their first clinic appointment, either a transplant coordinator or transplant clinic office staff member would introduce the study and inquire about the patient's interest in hearing about it. A Bachelors-level research assistant (RA) was present at all transplant clinics to recruit and consent all interested patients. Once notified by the clinic staff, the RA provided details of the study to the patients before proceeding to obtain informed consent and contact information for telephone interviews. Patients' contact information was then forwarded to the SRP of UCSUR through a secure, password-protected website to conduct the telephone interview. A trained SRP interviewer contacted the patients at their indicated time of availability for the interview. During the phone call, the SRP interviewer would introduce him/herself and ascertain the patient's availability before proceeding with the telephone interview. The baseline Time 1 data collection included assessments of culturally-related factors, psychosocial characteristics, transplant-related beliefs, demographics, and health-related for the parent design. The interview time for this phase averaged 70 minutes. Study participants were paid \$40 at the completion of the Time 1 interview.

The Time 2 interview occurred after a study participant completed all the required pre-transplant screening and was evaluated by the transplant team. Time 2 data collection involved accessing the patient's medical records to determine if he/she had completed the KT evaluation and whether he/she had been accepted or rejected for transplant by the transplant team. The patient's information was abstracted from a UPMC medical record database for transplant-related health information such as the number of potential living kidney donors that were evaluated, any medical contraindications for KT for either the patient or the transplant donor, type of KT that patient would receive (i.e. living or deceased donor), patient's wait list status, and physical disposition. Time 2 also involved a telephone interview with each participant that

lasted approximately 20 minutes. This interview assessed the patients' perceptions of the quantity and quality of contact with providers from the transplant team (including renal physicians, surgeons, transplant coordinators and other affiliated health care professionals), their transplant decision-making, and their health related quality of life. Patients were paid \$20 for completing the Time 2 interview. The key outcome of interest for the current study was time taken to complete KT evaluation. Time to complete KT evaluation was calculated in days, and was the difference between the date when a transplant decision was made (either accepted or rejected for KT by the transplant team) and the subject's first transplant clinic date. This time was calculated for all participants including those who did not complete the KT evaluation by the time of the data pull. For those participants who discontinued KT evaluation or died before completing the KT evaluation, the date of discontinuation or death was noted in the medical record and utilized for the study end-point.

Data collection for the study was from March 2, 2010 to October 24, 2012. During this period, 1,726 patients were scheduled for KT evaluation at the Starzl Transplant Clinic and 1,325 were eligible to participate in the study. Of those eligible, a total of 1,224 patients consented to participating in the study—yielding a 92% response rate—137 patients refused participation and 2 were discharged from the clinic before they could be approached for the study. Among those who consented to participate in the study, 1,152 completed the Time 1 interview. As of the data pull date, 1,134 patients had completed their Time 2 interviews. Four cases were removed from the study because they were transplanted at another transplant center before completing the KT evaluation at Starzl. A total of 1,130 participants were considered in the current analysis.

### **3.3 STUDY VARIABLES AND MEASUREMENT**

#### **3.3.1 Demographic Variables**

Self-reported demographic information collected during the interview included age, race, marital status, gender, education, insurance coverage and income. Race data were collected using a self-report measure that allowed patients to choose from a list of race categories, or to list their self-identified race in an “other” field (Mays, Ponce, Washington, & Cochran, 2003). Coding of race data resulted in three categories: non-Hispanic white, non-Hispanic African American, and other (i.e. all other race combinations). Patients who indicated more than one race where African American was one of the races selected were counted as African American for the analysis. Such a procedure is consistent with research practice in race and health research, and is done so because a person who indicates “African American” in his/her race selection is likely to have experiences shared by other African Americans patients.

#### **3.3.2 Medical Factors**

Because ESRD patients are known to suffer from illness comorbidity, which in turn affects perceived illness burden, a measurement of illness comorbidity and controlling for its influence on illness burden is necessary (Janssen et al., 2008). The Charlson Comorbidity Index is a measure of medical comorbidities using a weighted index that considers a patient’s age and the number and seriousness of comorbid disease(s) the patient has to predict the ten-year mortality for the patient (Charlson, Pompei, Ales, & MacKenzie, 1987; Jassal et al., 2005). An objective measure of illness comorbidity is different from illness burden discussed below, which is the patient’s subjective evaluation of the illness intrusiveness.

### 3.3.3 Independent Variables

*Illness Burden* Illness burden was measured using the “Burden of Kidney Disease” subscale of the Kidney Disease Quality of Life-Short Form (KDQOL-SF) (Hays, Kallich, Mapes, Coons, & Carter, 1994). The KDQOL-SF is a 79-item self-report measure with the SF-36 health survey as its generic core. The SF-36 is a short-form 36-item health survey using eight multi-item measures for assessing physical and mental health status (Hays, Sherbourne, & Mazel, 1993). The “Burden of Kidney Disease” subscale (see Appendix A) is a measurement of patients’ perception of ESRD illness burden or illness intrusiveness (Kimmel & Patel, 2006). Perceptions of illness burden may not correspond with functional status assessments because it is known that illness impact varies across individuals (Devins, 1994; Kimmel & Patel, 2006). Hence, a subscale such as this is pertinent for measuring patients’ perceived illness burden independent of their actual physical functioning and disease state. The subscale consists of three items. Respondents rated the extent to which each item described their ESRD on a scale from 1 (definitely true) to 5 (definitely false). For each item, the highest possible score of 5 indicated lowest burden. Therefore each item was reverse coded so that higher scores indicated higher illness burden. The summative score was then averaged to obtain the illness burden score. In this study, illness burden was a predictor variable, and would also be examined as a potential moderator between social support and time taken to complete KT evaluation.

The KDQOL-SF has been found to be a reliable and valid tool for both kidney dialysis and transplant patients (Barotfi et al., 2006; Hays et al., 1994). With regard to validity, the KDQOL-SF correlated significantly with the number of hospitalization days over a six-month period. It produced reliability estimates of Cronbach’s  $\alpha$  over 0.75 for all sub-scales except for one that was slightly below 0.75 (Hays et al., 1994). In this study, the Cronbach’s  $\alpha$  was 0.77.



***Social support.*** In this study, social support was examined in two aspects: social network size and perceived social support. These are often referred to as the objective and subjective measures of social support respectively, even though both are based on self-report (S. Cohen & Wills, 1985; Reblin & Uchino, 2008; Smith & Christakis, 2008). The structural measure of social support, social network size, was operationalized by asking participants to list the number of living relatives and friends that they had between the ages of 18 and 75 (the transplant program's acceptable age range for adult living kidney donors) in various categories including spouse, intimate partner, parents, siblings, cousins, aunts and uncles, friends, etc. (see Appendix A). All of these people were considered potential living donors even if the patient did not specifically ask them to donate, and were considered members of their social network. Such an operationalization of social network might bear a slight degree of inaccuracy on social network size because patients would have to exclude members in their social network who, despite providing social support, were excluded because they were not within the kidney donation age range (18-75). This operationalization was, therefore, a study limitation.

The overall score from the Interpersonal Support Evaluation List (ISEL-12) was used to measure perceived social support, also referred to as functional social support (see Appendix A). The scope of the ISEL corresponds with the prevailing theoretical premise on the domains of social support resources that likely facilitate coping with stress. Half of the items in ISEL consist of positive statements about social relationships and the remaining half are negative statements about social relationships. The reduced item ISEL-12 measures functional support on the domains of “tangible”, “appraisal” and “belonging” support, without any reference to a time frame. Each domain consists of four questions that yield a subscale and they aggregate to provide an overall functional support score. The “tangible” subscale measures perceived

availability of material aid or help with favor or errands, the “appraisal” subscale measures the perceived availability of having someone to talk to about one’s problems, and the “belonging” subscale measures the availability of people one can engage in activities with. Respondents rated the extent to which the sentence described the availability of the type of social support in their lives as true or false, where 1=Definitely False, 2= Probably False, 3= Probably True and 4=Definitely True. Items that were phrased in negative form were reverse coded. Higher scores indicate higher levels of social support.

Reliability of the ISEL when used with the general population was high ( $\alpha = .88$  to  $.90$ ) (S. Cohen, Mermelstein, Kamarck, & Hoberman, 1985). In terms of validity, the ISEL correlates positively with other scales such as the Inventory of Socially Supportive Behaviors that pertains to close friends, and with the Partner Adjustment Scale that assesses the quality of marital relationships (S. Cohen, et al., 1985). Other work has also demonstrated good reliability for ISEL-12 with Cronbach’s alpha for the three subscales ranging from  $.68$  to  $.71$ , and Cronbach’s  $\alpha = .86$  for the overall score (Myaskovsky et al., 2012). In this study, the Cronbach’s  $\alpha = 0.85$ .

The literature indicates that ISEL and the reduced item ISEL-12 can be measured as an overall scale, or a four sub-scale and a three sub-scale respectively (Brookings & Bolton, 1988; S. Cohen et al., 1985; Devins et al., 2001). In the ISEL-12, the three sub-scales are tangible, belonging and appraisal support, which excludes the self-esteem sub-scale found in the original ISEL. Cohen and colleagues (1985) maintain that the sub-scales have displayed independence from one another, that is, they measure the separate functions of social support hence justifying ISEL as a four-factor model, or in the case of ISEL-12, a three-factor model. However, other analyses have found high correlations among the sub-scales and demonstrated that ISEL could be examined as an overall single-factor model (Brookings & Bolton, 1988; Devins et al., 2001).

A confirmatory factor analysis was performed for this study to determine if the overall scale was more valid than the three sub-scales in the ISEL-12. A theory-driven model for construct validation, the confirmatory factor analysis allows for confirmation of the factors or constructs, the number of their dimensions and their commonality underlying a measurement (Brown, 2012; Schreiber, Nora, Stage, Barlow, & King, 2006). It is used to observe the relationship between an observed set of variables (or measures) with the latent variable (factor), and the aim is to assess if the data fit the hypothesized model (Brown, 2012). The confirmatory factor analysis for this study sample indicated that one overall scale was more valid than the three sub-scales. Table 3 reports the factor loading for the three sub-scales of appraisal, belonging and tangible support, and it can be seen that they loaded heavily on one component suggesting a single-factor model. That is, the responses from the study participants suggested that their perceived social support was not clearly distinct according to the sub-types of appraisal, belonging and tangible support. A plausible explanation could be that there is much overlap or correlation in the types of social support, and that when someone provides social support, it is usually more than one type of social support (Brookings & Bolton, 1988). For example, item 6 relates to appraisal support and item 9 pertains to belonging support. A respondent might perceive that being able to find a person to talk to when dealing with a personal problem would be the same person that he/she could find company for lunch with and thus would not distinguish between the types of perceived social support.

### **3.3.4 Dependent Variable**

The dependent variable for this study was time taken to complete KT evaluation and was measured in the number of days from the first transplant clinic date until the date when a transplant decision was made (either accepted or rejected for KT by the transplant team). For those participants who discontinued KT evaluation or died before completing the KT evaluation, the date of discontinuation or death was noted in the medical record and utilized for the study outcome.

Table 2. ISEL-12 Factor Analysis Component Loading

	Component		
	1	2	3
1. <sup>b</sup> If I wanted to go on a trip for a day (for example, to the country or mountains), I would have a hard time finding someone to go with me. (Reversed item)	.665	.221	-.008
2. <sup>a</sup> I feel that there is no one I can share my most private worries and fears with. (Reversed item)	.653	.216	.345
3. <sup>t</sup> If I were sick, I could easily find someone to help me with my daily chores.	.587	-.295	-.154
4. <sup>a</sup> There is someone I can turn to for advice about handling problems with my family.	.639	-.361	.344
5. <sup>b</sup> If I decide one afternoon that I would like to go to a movie that evening, I could easily find someone to go with me.	.660	-.329	-.013
6. <sup>a</sup> When I need suggestions on how to deal with a personal problem, I know someone I can turn to.	.661	-.401	.338
7. <sup>b</sup> I don't often get invited to do things with others. (Reversed item)	.585	.347	-.121
8. <sup>t</sup> If I had to go out of town for a few weeks, it would be difficult to find someone who would look after my house or apartment (the plants, pets, garden, etc.) (Reversed item).	.614	.355	-.238
9. <sup>b</sup> If I wanted to have lunch with someone, I could easily find someone to join me.	.665	-.271	-.365
10. <sup>t</sup> If I was stranded 10 miles from home, there is someone I could call who could come and get me	.642	-.149	-.353
11. <sup>a</sup> If a family crisis arose, it would be difficult to find someone who could give me good advice about how to handle it. (Reversed item)	.514	.424	.358
12. <sup>t</sup> If I needed some help in moving to a new house or apartment, I would have a hard time finding someone to help me. (Reversed item).	.598	.392	-.102

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<sup>a</sup> Denotes appraisal support, <sup>b</sup> Denotes belonging support, <sup>t</sup> Denotes tangible support

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### **3.3.5 Data Analysis Plan**

As part of preliminary analyses, all variables were examined for measures of central tendency, dispersion, skewness, and kurtosis, to determine that assumptions for statistical testing were met. For continuous variables such as age, illness burden, social network size, and perceived social support, the means, median and modes were determined, and histograms were used to examine their distribution and identify outliers. Comparison of predictor variables by demographic groups were examined using chi-squared tests for categorical variables, and Kruskal-Wallis for continuous variables, to examine for possible confounding effects with illness burden, social network size and perceived social support; any confounders were included in the final model. The non-parametric Kruskal-Wallis test was utilized for Charlson-comorbidity index if the assumptions of normality and homogeneity of variance were not met. Survival analyses using the Kaplan-Meier method and Cox regression was used to examine the relationships of the proposed variables in the conceptual model. The data were analyzed using SPSS version 21.

Specific Aim 1 was designed to describe how ESRD patients undergoing KT evaluation differed by age, gender, race, and income by illness burden and social support characteristics: social network size and perceived social support. Descriptive statistics were used to characterize patients' age, gender, race, income, illness burden, social network size, and perceived social support. Cross-tabulations were performed to examine how gender, race and income groups differed in their levels of illness burden, social network size and perceived social support. If the overall chi-squared test was statistically significant, pairwise comparisons were performed to examine how the groups differed. For the pairwise comparisons, a Bonferonni adjustment was applied. The continuous variables age and Charlson comorbidity index were assessed regarding assumptions of normality to justify utilization of parametric statistical analysis.

However because the assumptions of normality and homogeneity of variance were not met for these variables, Kruskal-Wallis tests were performed to examine their associations with illness burden, social network size, and perceived social support.

Specific Aim 2 was designed to evaluate how illness burden affected time to complete KT evaluation completion. Kaplan-Meier survival analysis was used to examine how levels of illness burden differed in patients' time to complete KT evaluation. Cox regression was used to examine if illness burden influenced the rate of KT evaluation completion, and if the rate differed across different levels of illness burden.

Specific Aim 3 focused on assessing how social support (social network size and perceived social support) affected time to complete KT evaluation. Similar to the analytic methods used for Aim 2, Kaplan-Meier survival analysis examined how social network size and perceived social support affected the rate of KT evaluation. Cox regression was used to test if social network size and perceived social support were significantly associated with the rate of KT evaluation completion, and if the completion rate differed across the different levels of social network size and perceived social support.

Specific Aim 4 focused on determining the moderating effect of social support characteristics (that is, social network size and perceived social support) on ESRD illness burden in the time to complete KT evaluation using a Cox regression model.

To test whether social support moderates illness burden in the completion of KT evaluation, illness burden, social network size and perceived social support were included in the first step. For the second step, the interaction term of illness burden and social network size, and the interaction term of illness burden and perceived social support were added to the regression

model. A moderation effect was present if there was any significant  $R^2$  change in the second model.

To test the predictor variables in time to complete KT evaluation, based on analyses for Aims 2 and 3, variables with a significant ( $p < .05$ ) inter-correlation were considered for removal from the final model. On the other hand, variables with a significant ( $p < .05$ ) association with KT evaluation completion rate from a Cox regression model were considered for inclusion in the final model.

The study data are, by their nature, survival data because they measured the time until the occurrence of a particular event: the length of time before a specific event of interest occurred, which in this case was KT evaluation completion. Ubiquitous in medical studies, survival analysis is a statistical tool that evaluates time to event—where time is the dependent variable—and estimates the underlying distribution of the survival time variable and assesses how survival time is related to a set of independent variables (Willett & Singer, 1993). While classically the event referred to the occurrence of death, it can refer to the occurrence of any specified event, such as relapse, time to hospital discharge, etc. (Luke & Homan, 1998). Survival analysis makes accommodation for censoring of observation or data. Censoring occurs when there is incomplete information on the measurement of the event. It can occur when a participant drops out of the study, dies, is lost to follow-up or does not experience the event by the end of the data collection period (Luke & Homan, 1998). Not all participants completed the KT evaluation by the data pull date (February 2014). Because these participants still provided information on how much time they had spent in the evaluation process, they were included in all analyses. It is important to analyze time-to-event data using a method that can appropriately incorporate censored data, such as survival analysis methods using Kaplan-Meier estimators and curves (Kaplan & Meier, 1958)



and Cox regression (Cox, 1972). Kaplan-Meier survival analysis and Cox regression modeling make proper allowances for those observations that are censored, and also makes use of the information from these subjects up to the time when they are censored (Willett & Singer, 1993).

The Kaplan-Meier estimator is a non-parametric estimator of the survival function for time-to-event data, which may include censoring (Luke & Homan, 1998). It provides an estimate of the true survival function and allows for the survival functions of different groups to be compared. The survival function indicates the probability of surviving or being event-free beyond a certain time point, and the survival function can be plotted against time to produce the profile of survival and time (Singer & Willett, 1991). The hazard function is the probability of experiencing the event in an infinitely small time period between  $y$  and  $y + \partial y$  given that the subject has survived up till time  $y$ . Alternatively, the one-minus survival curve, the complement of the survival function, shows the probability of experiencing the event by a certain time point. Visual examinations of the Kaplan Meier survival, one-minus survival, and hazard function curves can inform on the survival and hazard functions of groups, and how the groups may differ in these functions. Using non-parametric statistical tests, such as the log-rank test, the Kaplan-Meier method of survival analysis can also formally test if group differences in survival exists (Luke & Homan, 1998; Willett & Singer, 1993). The log-rank applies equal weights to every time point in calculating the number of actual event occurrence to the number of expected events for each time point in the study (Luke & Homan, 1998).

Cox regression, commonly known as a proportional hazards model, is a semi-parametric regression model that allows for the use of categorical and continuous variables to estimate the hazard function (event risk). That is, it assesses how predictors or covariates contribute to the rate of experiencing an event (Luke & Homan, 1998; Willett & Singer, 1993). The proportional

hazards model assumes proportionality of hazards over time. That is, it assumes that the variables exert constant effect on the hazard rate across time; the variables do not interact with time. Therefore diagnostics for potential presence of time-dependency in covariates were performed to test this assumption, and a time-varying Cox regression model would be used in the final model, if suggested by the diagnostics.

For this study, a participant's evaluation time was censored if the participant discontinued the KT evaluation, if the subject died before completing the evaluation process, or if the subject had not completed the KT evaluation by the data pull date. In this study, the original outcome of interest was time to event measured in number of days. However, Cox survival analysis uses hazard ratio, thus the outcome is expressed as the rate of KT evaluation completion, rather than the number of days to completion.

***Confounding variables.*** To examine the unique relationship between illness burden and social support with time to complete KT evaluation, demographic variables and the Charlson comorbidity index were controlled, because they are known potential confounders (Alexander & Sehgal, 2001; Berkman, Leo-Summers, & Horwitz, 1992; Brummett et al., 2001; Cukor et al., 2007; Kimmel, 2000a; Patzer et al., 2012; Schold et al., 2011; Turner & Marino, 1994; Vamos et al., 2009; Weisbord et al., 2005; Weng et al., 2005).

***Missing data.*** Due to the data collection methods, which were telephone-based and used highly standardized and well-tested procedures, very complete data for participants was expected such that there would be minimal missing data. Subjects with missing values on any variable would not be included in the analysis. For summary variables, such as perceived social support and illness burden, if at least 50% of the items in the scale were accounted for, then the data were included in the analysis.

## **4.0 RESULTS**

### **4.1 PRELIMINARY ANALYSIS**

There were a total of 1,130 participants in this study. Approximately 11 per cent of the observations were censored either because the participant discontinued the KT evaluation, the participant died before completing the evaluation process, or the participant had not completed the KT evaluation by the data pull date. Regarding the distribution of all transplant decision times (including those which are censored), the range was 1,322 days (min. 1 day and max. 1323 days), and the median transplant decision time was 353 days. For subjects who completed the KT evaluation by the data pull date (excluding censored observations), the range on transplant decision time was 1,197 days (min.1 day, max. 1,198 days) and the median transplant decision time was 336 days.

Table 3 offers an overview of the patients' demographic profile and the key study variables. The variables of interest, Charlson Comorbidity Index, illness burden, social network size and perceived social support were examined for central tendency.

Table 3. Study Sample Characteristics

Demographics	
Gender – n (%)	
Male	700 (61.9)
Female	430 (38.1)
Race – n (%)	
Non-Hispanic white	776 (68.7)
Non-Hispanic black	260 (23.0)
Other	94 (8.3)
Age – mean (SD)	
Range (18-92)	55.8 (13.47)
< 40	147 (13.1)
41-50	216 (19.3)
51-60	303 (27.0)
61-70	322 (28.7)
> 71	134 (11.9)
Income – n (%)	
Under \$25,000	526 (49.1)
\$25,001 to \$ 50,000	270 (25.2)
Over \$50,000	276 (25.7)
Treatment modality – n (%)	
Hemodialysis	552 (52.5)
Peritoneal dialysis	114 (10.8)
Pre-dialysis	385 (36.6)
Key Study Variables – median (min-max)	
Charlson co-morbidity index	3 (0-19)
Illness burden	4 (1- 4)
Perceived social support	44 (16-48)
Social network size	17 (0-127)

The Kaplan-Meier estimators were utilized to assess categorical demographic variables for time to complete KT evaluation. A visual estimation of the one-minus survival curves indicate that there was no significant difference between males and females in their KT completion time (see figure 2). In Figure 3, it is visible that whites were more likely than African Americans and other races to complete KT evaluation. The distance between the one-minus survival curves of whites compared to African

Americans was greatest at the start before narrowing towards the end, indicating that 1) the comparative advantage that white had over African Americans in completing KT evaluations was prevalent mainly at the earlier phase of the evaluation, and 2) the hazard rate was not constant and this was indicative of time dependency, which would be further discussed in the final model. The one-minus survival curves show that the higher the income, the greater the chance of completing the KT evaluation (see figure 4). The distance between the curves appear proportionate, implying that the hazard rate for the completion of KT evaluation was constant over time for the three income groups.

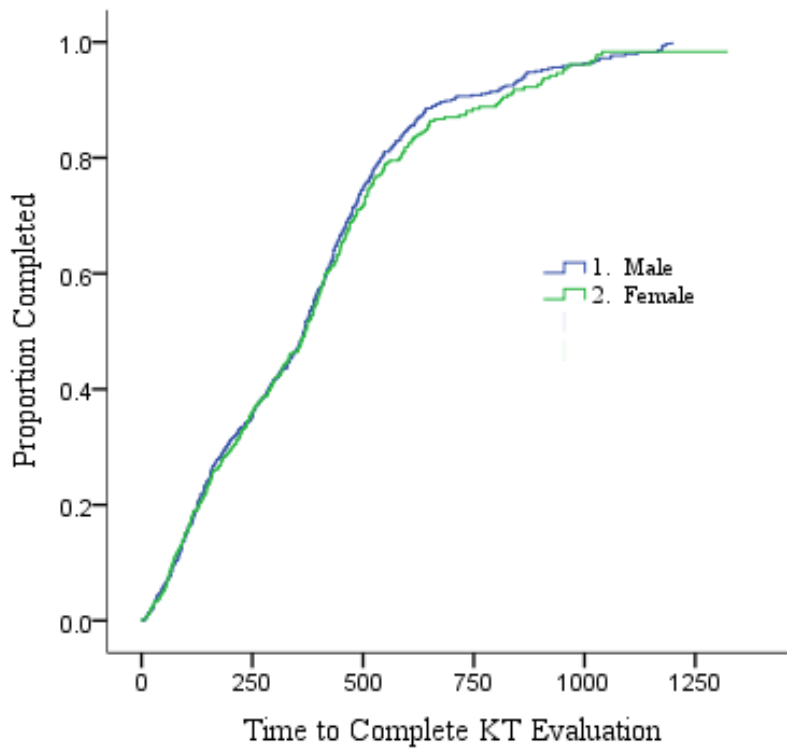


Figure 2. Kaplan-Meier one-minus survival curves showing cumulative KT evaluation completion rates by gender

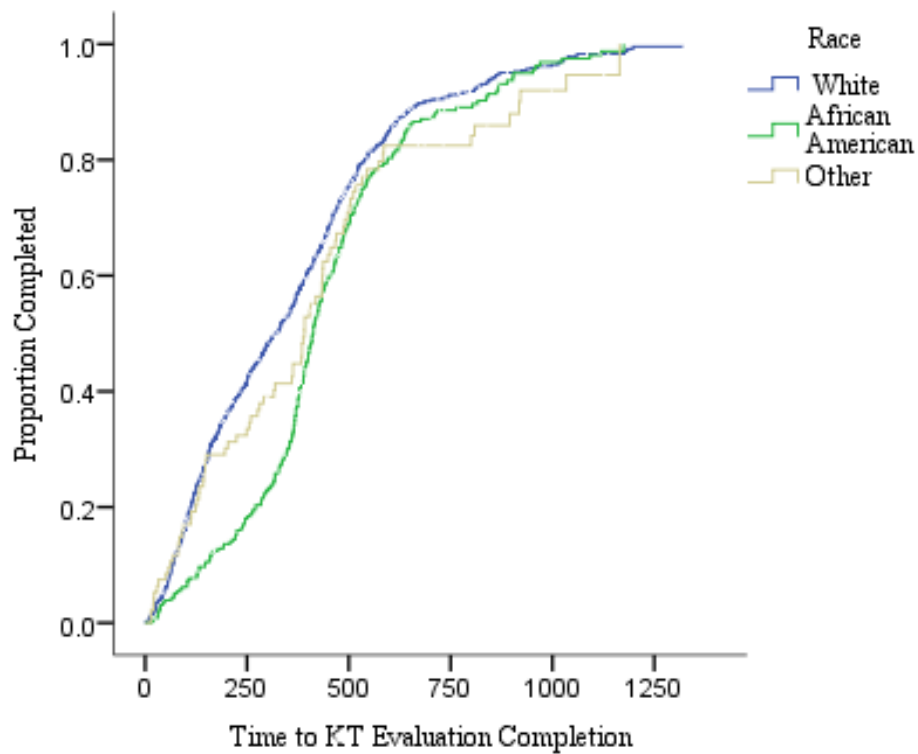


Figure 3. Kaplan-Meier one-minus survival curves showing cumulative KT evaluation completion rates by race groups

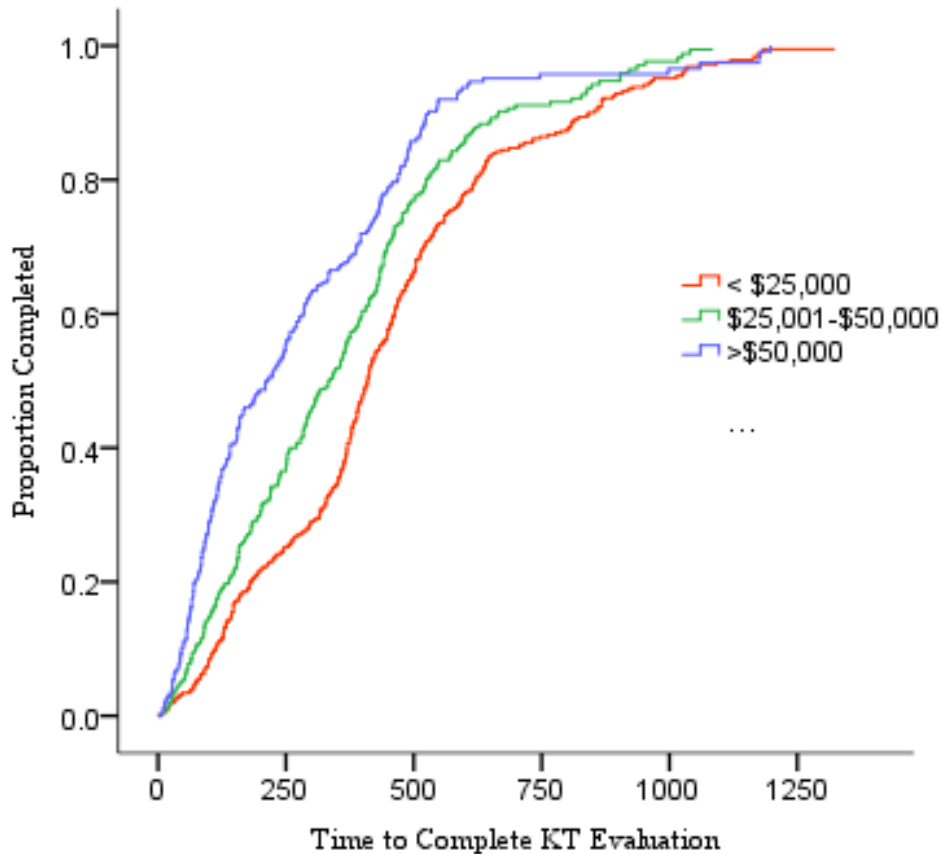


Figure 4. Kaplan-Meier one-minus survival curves showing cumulative KT evaluation completion rates for income groups

The above curve estimators were confirmed with the log-rank statistical tests, as shown in Table 4, which also provides the median survival time. The median survival time refers to the number of days before half of the participants in their respective groups completed their KT evaluations. The log-rank statistics indicates if differences between groups exist. Compared to whites, African Americans had a median survival time that was 3.5 months longer than whites. Study participants earning under \$25,000 annually had a median survival time six months longer than those earning above \$50,000, and a median survival time of 2.5 months longer than those earning between \$25,001 and \$50,000.

Table 4 Median KT Evaluation Completion Time for Gender, Race and Income Groups

	Median	95% Confidence Interval
Gender		
Male	367	347-387
Female	370	339-401
Log-rank $\chi^2(1) = .79, p = .37$		
Race		
White	320	288-352
African American	413	394-432
Other	391	348-434
Log-rank $\chi^2(2) = 13.184 p = .001$		
Income Groups (\$)		
< 25,000	410	391-429
25,001-50,000	336	293-379
> 50,000	213	164-262
Log-rank $\chi^2(1) = 63.74 p < .001$		

Cox regression was utilized to examine how the continuous variables of age and Charlson Comorbidity Index related with time to complete KT evaluation. Because of the wide age range (18-92 years) age was analyzed by 10-year unit instead of single-year unit for more meaningful interpretation of the results. Age was significantly related to KT completion time, hazard ratio = .722, 95% CI = .55-.95,  $p = .021$ . Every decade increase in age reduced KT completion rate by 27.8 per cent. Charlson Comorbidity Index significantly related with time to complete KT evaluation, hazard ratio = .830, 95% CI = .74-.93,  $p = .002$ . Every increase in Charlson Comorbidity Index is associated with a 17 per cent reduction in chance of completing KT evaluation.

To gain insight into the patients' illness comorbidity profile, Kruskal-Wallis tests were performed, indicating race difference in Charlson Comorbidity Index. African Americans had



significantly higher illness co-morbidity compared to whites and other races  $\chi^2 (2, N = 1030) = 144.51, p < .001$ . Lower income was also significantly associated with more illness comorbidity  $\chi^2 (2, N = 1072) = 14.69, p = .001$ . Age and gender were not related to Charlson Comorbidity Index.

## 4.2 ANALYSIS RELATED TO AIM 1

Hypothesis 1a: Patients who are older, male, whites and from higher income groups have lower illness burden than those who are younger, female, non-white and from lower income groups.

Hypothesis 1b: Patients who are younger, female, white and from higher income groups have bigger social networks and higher level of social support than those who are older, male, non-white and from lower income groups.

Illness burden, perceived social support and social network size were assessed for assumptions of normality. They were determined to be highly skewed and could not be corrected with data transformation and were recoded into quartiles for analyses. In order to understand how the study participants differed by their demographic characteristics in relation to illness burden, social network size and perceived social support, chi-square and Kruskal-Wallis tests were utilized for categorical and continuous variables respectively. The cross-tabulations for associations between categorical variables are indicated in Appendix B.

There was no relationship between gender and race with illness burden. Income was significantly associated with illness burden  $\chi^2 (9, N = 1072) = 15.88, p = .014$ ; and pairwise comparisons demonstrated that those earning less than \$25,000 annual income had significantly higher illness burden. Kruskal-Wallis test determined that there were no relationships between age and illness burden. Charlson Comorbidity Index and illness burden were found to be

associated  $\chi^2 (= 10.98, p = .012)$ . Other than gender, the results otherwise support the hypothesis that patients who are younger, white and with higher income have lower illness burden than those who are older, non-white and with lower income.

Chi-square tests confirmed that gender was not associated with either social network size or perceived social support. Race was associated with social network size  $\chi^2 (6, N = 1130) = 16.86, p = .01$ , and pairwise comparisons found that African Americans had significantly larger social networks than whites. There was also a significant association between race and perceived social support  $\chi^2 (6, N = 1130) = 13.39, p = .04$ , with pairwise comparisons indicating that whites had significantly lower social support than African Americans. Income was significantly associated with social network size  $\chi^2 (9, N = 1072) = 18.38, p = .005$  and perceived social support  $\chi^2 (9, N = 1072) = 30.89, p < .001$ . Pairwise comparisons indicated that lower income patients had significantly smaller social network size and lower perceived social support. Kruskal-Wallis tests determined that there were no relationship between age and perceived social support, although age was associated with social network size  $\chi^2 (= 35.21, p < .001)$ , whereby compared to the older ones, the younger study participants had significantly bigger social network size. Association was also found between Charlson Comorbidity Index and perceived social support  $\chi^2 (= 9.02, p = .029)$ , although none was found with social network size. Because gender that had no associations with social network size and perceived social support, and African Americans had bigger social networks and higher perceived social support, the hypothesis that patients who are younger, female, white and from higher income groups have bigger social networks and higher level of social support than those who are older, male, non-white and from lower income groups could not be supported.

### 4.3 ANALYSIS RELATED TO AIM 2

Hypothesis 2: Lower illness burden is associated with a higher rate of KT evaluation completion.

Kaplan Meier survival analysis was performed to test if illness burden was associated with time to complete KT evaluation. The Kaplan-Meier one-minus survival curve estimators depicted in Figure 5 show that the different illness burden quartiles curves were closely stacked, suggesting unlikely difference among illness burden quartile levels in their time to complete KT evaluation. This observation was confirmed with the log-rank test  $\chi^2(1) = 5.302, p = .15$ . Table 5 shows the median survival time and hazard ratio for each illness burden quartile. The median survival time indicates the number of days it took before half of the study participants in each group completed KT evaluation. The Cox bivariate regression indicates that illness burden had no significant influence on time to complete KT evaluation. Based on these results, hypothesis 2 was thus not supported. Illness burden was not associated with time to complete KT evaluation.

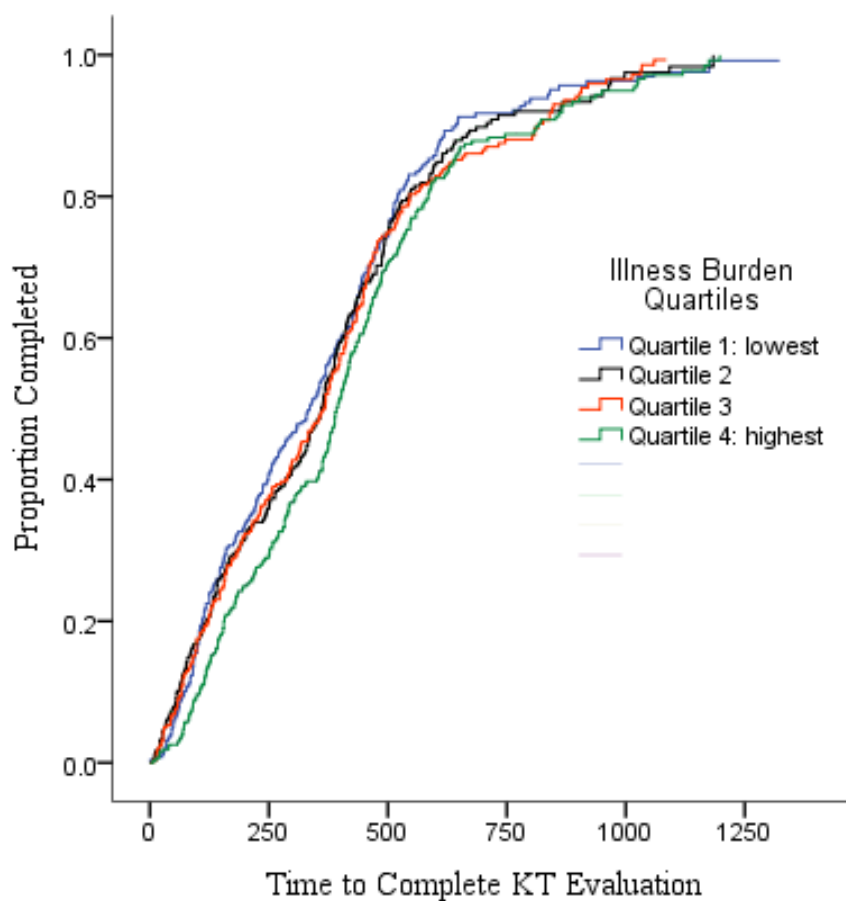


Figure 5. Kaplan-Meier one-minus survival curves showing the proportion of patients in each illness burden quartile completing KT evaluation

Table 5. Median KT Evaluation Completion Time and Cox Bivariate Analysis for Illness Burden Quartiles

	*Median	95% CI	Hazard Ratio	<i>p</i> -value
Quartile 1	336	[287, 384]	Reference Group	
Quartile 2	361	[331, 391]	.95	.577
Quartile 3	367	[328, 406]	.94	.455
Quartile 4	392	[370, 414]	.82	.029

\* Log rank  $\chi^2(3) = 5.30, p = .151$

#### 4.4 ANALYSIS RELATED TO AIM 3

Hypothesis 3a: A larger social network size is associated with a higher rate of KT evaluation completion.

Hypothesis 3b: Greater social support is associated with a higher KT evaluation completion rate.

Social support was examined on two characteristics: social network size and perceived social support. Similar to the analytic methods used for Aim 2, Kaplan Meier was used to test if these two predictors were associated with time to complete KT evaluation. A visual appraisal of the closely laid Kaplan-Meier one-minus survival curves in Figure 6 suggests little difference between the network size quartiles and their time to complete KT evaluation. Cox bivariate analysis demonstrated no significant association between social network size and time to complete KT evaluation, Log Rank  $\chi^2(3) = 4.088, p = .25$  (see Table 6). Hypothesis 3a is hence rejected.

Table 6. Median KT Evaluation Completion Time and Cox Bivariate Analysis for Social Network Size Quartiles

	*Median	95% CI	Hazard Ratio	<i>p</i> -value
Quartile 1	379	[350, 408]	Reference Group	
Quartile 2	360	[328,391]	1.196	.577
Quartile 3	368	[334, 402]	1.130	.455
Quartile 4	370	[331, 409]	1.141	.029

Log Rank  $\chi^2(3) = 4.09, p = .25$

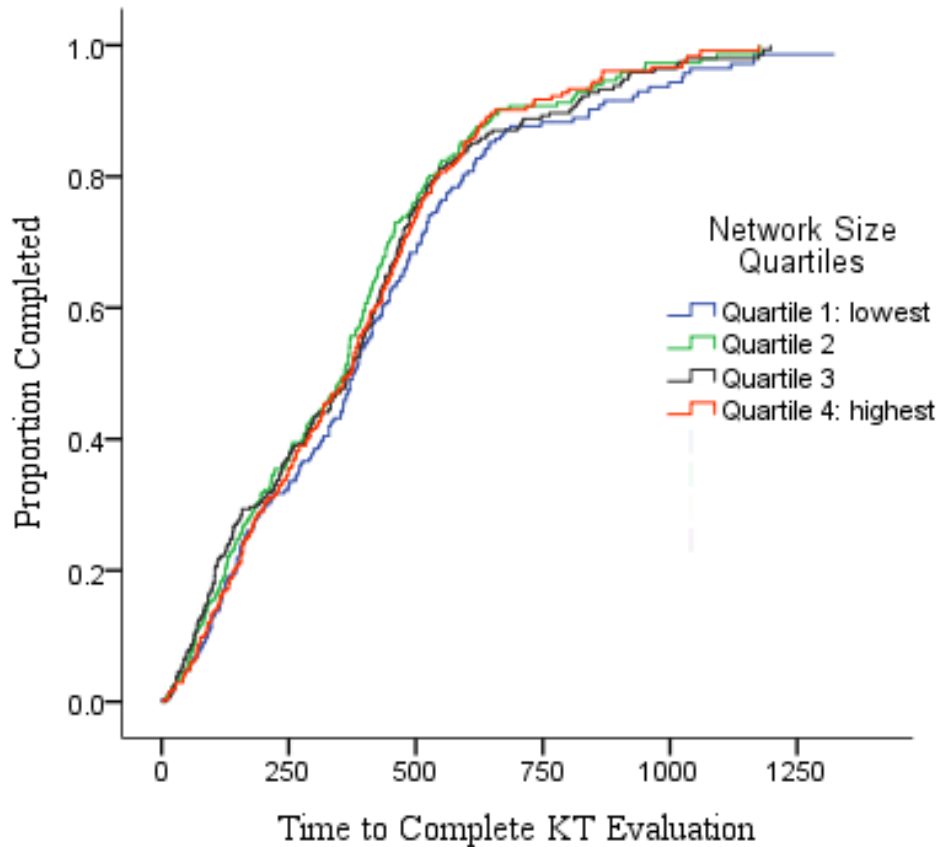


Figure 6. *Kaplan-Meier one-minus survival curves showing the proportion of patients in each social network size quartile completing KT evaluation*

In contrast, bivariate analysis using Cox regression survival indicated perceived social support was significant in influencing time to complete KT evaluation  $\log\text{-rank } \chi^2(3) = 13.49, p = .004$ . Further, it determined that study participants in quartiles 2 and 4 were 28.6 per cent and 36.8 per cent respectively more likely than those the lowest quartile to complete KT evaluation (see Table 7). An estimation of the Kaplan-Meier one-minus survival curves (Figure 7) reveal that the curves for perceived social support quartiles 1 and 4 were most distinctively apart, indicating that study participants in the highest perceived social support quartile had a higher chance than those with the lowest social support in completing KT evaluation. The median KT

evaluation time indicate that patients in the highest perceived social support quartile took the least number of days to complete KT evaluation. Hypothesis 3b is supported in that greater perceived social support was associated with a shorter KT evaluation time.

Table 7. Median KT Evaluation Completion Time and Cox Bivariate Analysis for Perceived Social Support Quartiles

	*Median	95% CI	Hazard Ratio	<i>p</i> -value
Quartile 1	420	[391, 449]	Reference Group	
Quartile 2	362	[329, 395]	1.286	.005
Quartile 3	342	[285, 399]	1.190	.063
Quartile 4	327	[285, 369]	1.368	.001

Log rank  $\chi^2$  (3) = 13.49, *p* = .004

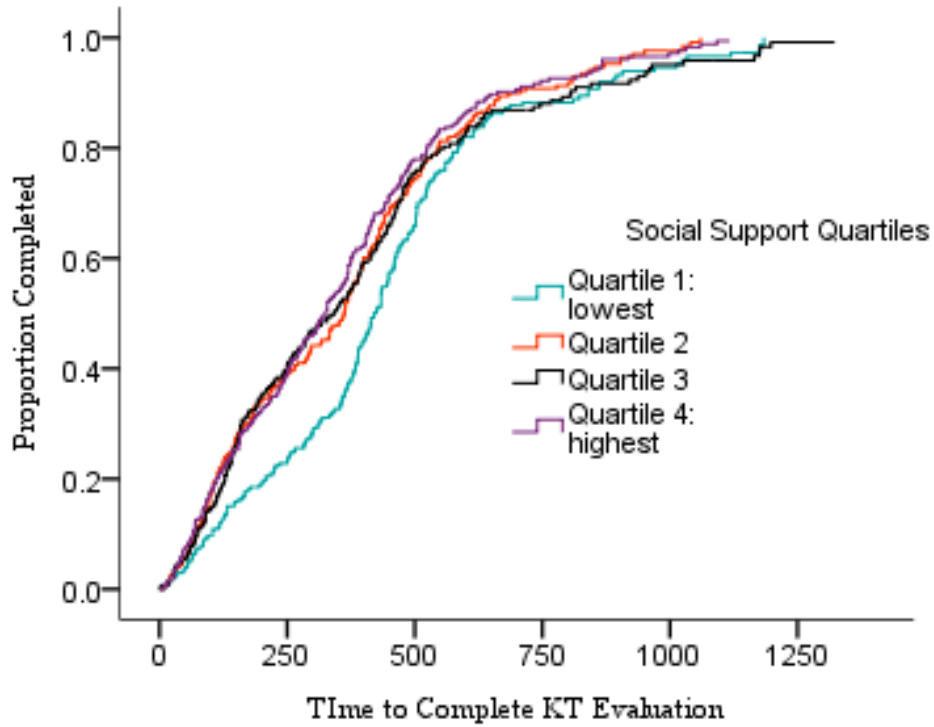


Figure 7. Kaplan-Meier one-minus survival curves showing the proportion of patients in each perceived social support quartile completing KT evaluation



#### 4.5 ANALYSIS RELATED TO AIM 4

Hypothesis 4: Social support moderates the impact of ESRD illness burden and improves the rate of KT evaluation completion.

Based on the earlier bivariate analysis of the demographic variables with time to complete KT evaluation, gender was the only variable assessed to be a confounder and was not included in the final model. Age, race and income were included in the final model because of their associations with time to complete KT evaluations, along with the predictor variables illness burden, social network size and perceived social support based on the study's conceptual model. Because of the wide age-range in this sample, age was analyzed by 10-year increments to enable more meaningful interpretations of the results. Dummy variables were created for categorical variables to allow for interpretation of the measures of association in the Cox regression output. The correlation matrix of regression coefficients was examined for potential multi-collinearity among the variables but none was found, hence allowing for all these variables to be included in the final model. A Cox regression was performed on time to complete KT evaluation after controlling for the participants' age, race, income and Charlson's co-morbidity index.

Table 8 shows the hazard ratio for the main effects of the variables on time to complete KT evaluation. After adjusting for age, race, income, comorbidity, illness burden, social network size and perceived social support, the following variables persisted in showing

differences in time to complete KT evaluation: race, income, age, comorbidity and social support levels.

Based on this output, patients enjoying the highest quartile of perceived social support were 23 per cent significantly more likely than those from the lowest quartile of perceived social support to complete KT evaluation (HR 1.233,  $p = .028$ ). Compared to patients from the lowest income group with an annual income under \$25,000, study participants those who earned \$25,001 to \$50,000 (HR 1.274,  $p = .003$ ) and those earning above \$50,000 annually (HR 1.710,  $p < .001$ ) were more about a quarter time and three-quarter times likely to complete KT evaluation, respectively. Increased age was significantly associated with increased time to complete KT evaluation (HR .946,  $p = .029$ ). For every decade increase in age, the likelihood of completing KT evaluation declined by 5.4 per cent. Similarly, higher Charlson Comorbidity Index was significantly associated with increased time to complete KT evaluation (HR .967,  $p = .010$ ), whereby each unit increase in Charlson Comorbidity Index saw a reduced rate of KT evaluation by 3.3 per cent.

Table 8. Hazard Ratios for Main Effects on Covariates for Time to Complete KT Evaluation

Variable	HR	CI	<i>p</i>
<b>Illness burden</b>			
Reference group: quartile 1 (lowest level)			
Illness burden quartile 2	.981	[.819, 1.175]	.833
Illness burden quartile 3	.991	[.825, 1.192]	.925
Illness burden quartile 4	.881	[.737, 1.054]	.895
<b>Social network size</b>			
Reference group: Quartile 1 (lowest level)			
Social network size quartile 2	1.058	[.879, 1.273]	.715
Social network size quartile 3	.980	[.820, 1.170]	.743
Social network size quartile 4	1.038	[.861, 1.252]	.825
<b>Perceived social support</b>			
Reference group: quartile 1 (lowest level)			
Perceived social support quartile 2	1.164	[.974, 1.392]	.077
Perceived social support quartile 3	1.057	[.875, 1.278]	.021
Perceived social support quartile 4	1.233	1.022, 1.487]	.020
Age-by-decade	.946	[.899, .944]	.003
Charlson co-morbidity index	.976	[.959, .994]	.005
Variable	HR	CI	<i>p</i>
<b>Income</b>			
Reference group: < \$25,000			
Income \$25,001-\$50,000	1.274	[1.086, 1.494]	.010
Income > \$50,000	1.710	[1.450, 2.018]	< .001
<b>Race (Reference group: white)</b>			
African American	.849	[.724, .995]	< .001
Other	.898	[.706, 1.142]	.438

The Cox survival analysis method assumes proportionality of hazard assumption, hence the next step required utilizing a time-variant model that tested for possible time dependency of the covariates. With the exception of illness burden and social network size that were not

associated with time to complete KT evaluation, the remaining variables were evaluated for possible interaction with time. Based on visual estimation of the the Kaplan-Meier curves, income did not display any time-dependency (Figure 4), indicating that the hazard ratio of income was constant across time. The shapes of the Kaplan-Meier curve estimators suggested time-dependency for race (Figure 3) and perceived social support (Figure 7), and time-dependent covariates were therefore produced for these variables. Because the continuous variables age and Charlson Comorbidity Index could change over time that implied a possible time interaction, they were also examined with their corresponding time-dependent covariates. A time-dependent covariate is assumed to be related to the hazard rate and varies the effect of the hazard rate across time, hence its effects on the model must be assessed (Luke & Homan, 1998). The revised model therefore included the predictor variables along with their time-dependent covariates for those that are assessed to be time-dependent.

A successive series of re-evaluation of the model was undertaken that involved the individual removal of the non-significant time-dependent covariate, beginning with the covariate with the highest non-significant value, and the model re-evaluated. This continued until only time-dependent covariates with significant values ( $p < .05$ ) remained in the model. The non-significant time-dependent covariates were removed in this order: perceived social support quartile 4 ( $p = .192$ ), perceived social support quartile 2 ( $p=.135$ ), and Charlson Comorbidity Index ( $p = .116$ ). The resultant model was the final one displaying the covariates and their significant time-dependent covariates, if any (see Table 9).

Charlson Comorbidity Index was significant with time to complete KT evaluation (HR .974,  $p = .005$ ) in that every unit increase in comorbidity reduced KT completion rate by 2.4 per cent. Similar to the main effects model, participants earning \$25,001 to \$50,000 were about a

quarter times more likely than those earning below \$25,000 to complete KT evaluation (HR = 1.234,  $p = .01$ ), whereas those earning more than \$50,000 were 68 per cent more likely (HR = 1.675,  $pp < .001$ ) than the lowest income comparison group.

In a time-dependent Cox regression model, the hazard ratios of variables that are tested significant for time-dependency cannot be interpreted directly, but must consider the time-dependency covariate because the hazard rate is not equally applied across time. This limits the interpretation of the hazard function, which can also be vulnerable to erroneous interpretation (L. D. Fisher & Lin, 1999). Perceived social support was significant on time to complete KT evaluation ( $p = .021$ ) and it was also significantly time-dependent ( $p = .025$ ). In comparing the main effects and time-dependent output, the conclusion was that in general, higher perceived social support led to higher completion rate of KT evaluation, although the rate of completion was not constant for those with moderately high perceived social support (quartile 3) because of time-dependency effects. The main effects model suggest that increased age was significantly associated with reduced KT evaluation completion rate, however, its time-dependent character implied that their comparatively lower KT evaluation rate mitigated over time. Race had a time-varying effect on KT completion time for African Americans. Initially, African Americans had a lower rate of KT evaluation completion compared to whites but such a disadvantage was no longer true for the latter phase of the evaluation. The implications of these results would be discussed in the next chapter.

Table 9. Hazard Ratios for Time-Dependent Covariates for Time to Complete KT Evaluation

Variable	HR	CI	<i>p</i>
<b>Illness burden</b>			
Reference group: quartile 1 (lowest level)			
Illness burden quartile 2	.984	[.822, 1.179]	.862
Illness burden quartile 3	1.010	[.840, 1.213]	.919
Illness burden quartile 4	.895	[.748, 1.071]	.225
<b>Social network size</b>			
Reference group: Quartile 1 (lowest level)			
Social network size quartile 2	1.035	[.860, 1.246]	.715
Social network size quartile 3	.971	[.812, 1.160]	.743
Social network size quartile 4	1.021	[.847, 1.232]	.825
<b>Perceived social support</b>			
Reference group: quartile 1 (lowest level)			
Perceived social support quartile 2	1.175	[.983, 1.405]	.077
Perceived social support quartile 3	2.719	[1.165, 6.345]	.021
Perceived social support quartile 4	1.250	[1.036, 1.507]	.715
Time-dependent covariate for perceived social support quartile 3	.842	[.724, .979]	.025
<b>Age by decade</b>			
Age by decade	.657	[.499, .866]	.003
Time-dependent covariate for age-by-decade	1.071	[1.018, 1.126]	.007
<b>Charlson co-morbidity index</b>			
Charlson co-morbidity index	.974	[.957, .992]	.005
<b>Income</b>			
Reference group: < \$25,000			
Income \$25,001-\$50,000	1.234	[1.052, 1.447]	.010
Income > \$50,000	1.675	[1.419, 1.977]	< .001
<b>Race (Reference group: white)</b>			
African American	.036	[.011, .123]	< .001
Time-dependent covariate for African American	1.747	[1.416, 2.156]	< .001
Other	.909	[.715, 1.156]	.438

## 5.0 DISCUSSION

Several studies have examined the role of demographic factors in affecting kidney transplant (KT) evaluation completion (Alexander & Sehgal, 1998, 2001; Epstein et al., 2000; Kazley et al., 2012; Myaskovsky et al., 2012; Patzer et al., 2012). There are also studies that examined the influence of social support on KT evaluation completion (Cass et al., 2003; M. S. Fisher, 2006; Scandling, 2005; Steinman et al., 2001). Other than gender having inconclusive outcomes, the existing studies consistently show that patients who are older, African American, with lower income and lower social support have a lower rate of KT evaluation. The current study presented data on how demographic characteristics (gender, race, age and income), illness burden and social support characteristics (social network size and perceived social support) affected time to complete KT evaluation. Specifically, the goal of the study was to determine if social support moderated illness burden on time to complete KT evaluation. Results from this study partially supported the hypotheses. Overall, greater perceived social support significantly improved KT evaluation completion rate despite it not having a moderating effect on illness burden. Along with social network size, illness burden had no significant effect on time to complete KT evaluation. Demographic factors such as older age, lower income and being African American were associated with a lower rate of KT evaluation completion. This chapter discusses the results of the study in greater detail and provides an interpretation of the findings. The limitations of the study are discussed, followed by its implications on practice and future research.

## **5.1 ASSOCIATIONS OF DEMOGRAPHIC FACTORS WITH ILLNESS BURDEN AND SOCIAL SUPPORT CHARACTERISTICS**

The findings of the study indicate that gender had no association with illness burden, social network size and perceived social support, contrary to from other studies (House, 1987; Turner & Marino, 1994). The finding that whites had significantly lower social support compared to African Americans and other races confirms similar findings in some studies (Cetingok et al., 2008; Kimmel et al., 2003) but contradicted at least one other (Clark et al., 2008). Further, as in other studies, we found that lower income participants had greater illness burden (Gaylin et al., 1993; L. Plantinga et al., 2012), smaller social networks and lower perceived social support (Ajrouch et al., 2005; Turner & Marino, 1994). Older age was only linked to smaller social network size, a characteristic confirmed by some studies (Ajrouch et al., 2001; Ajrouch et al., 2005), but had no significant associations with illness burden and perceived social support. This study's findings that gender, race and age did not affect illness burden add to the already divergent conclusions in the literature on illness burden impact across demographic groups (Kimmel et al., 2003; Lenihan et al., 2013; Merkus et al., 1999; Weisbord et al., 2005). Based on outcomes of this study, the hypothesis that older, male, whites from higher income groups have lower illness burden than those who are younger, female, non-white and from lower income groups, could only be partially supported. Similarly, only partial support was found for the hypothesis that patients who are female, white, from higher income groups and younger have bigger social networks and higher levels of social support than those who are older, male, non-white and from lower income groups. The absence of full support for both hypotheses reflects the inconclusiveness in the existing evidence on how illness burden and social support characteristics differ by demographic characteristics.



## **5.2 PREDICTORS FOR KT EVALUATION COMPLETION**

Illness burden was not associated with time to complete KT evaluation, and no interaction was found between illness burden and social support. Therefore, the key conceptual hypothesis that social support moderates illness burden in the completion of KT evaluation could not be supported. Social support does not have a buffering effect on illness burden in the completion of KT evaluation. However, greater perceived social support was found to increase KT evaluation completion, suggesting main effects of social support. The covariates that significantly lowered the rate of KT evaluation completion were lower income, African American race, older age and greater illness comorbidity, however higher perceived social support significantly improved KT evaluation completion rate. Participants from other races also had a lower KT completion rate when compared to whites, although this finding was not significant. Contrary to findings from other studies (Alexander & Sehgal, 2001; Gaylin et al., 1993), gender was not associated with time to complete KT evaluation; and it was the only demographic factor demonstrating this characteristic.

### **5.2.1 Demographic Factors**

The study outcome indicating the lower KT evaluation completion rate for lower income patients was not surprising given other results (Gaylin et al., 1993; Kazley et al., 2012; Schold et al., 2011). A likely explanation is that people from lower income would have less personal resources and knowledge to negotiate the KT evaluation process (Browne, 2008; Clark et al., 2008; Kazley et al., 2012; Ozminkowski, White, Hassol, & Murphy, 1998; Schaeffner, Mehta, & Winkelmayr, 2008). For example, difficulty with transportation and costs has been cited as a reason why patients did not complete their KT evaluation (Kazley et al., 2012). Furthermore, lower income patients tend to have a lower level of perceived social support (Ajrouch et al.,

2005; Turner & Marino, 1994). The inadequate personal resources compounded with a lack of external resources render the lower income patients more susceptible in needing longer time to complete KT evaluation. Patients from lower income groups are also known to have higher associations with medical non-adherence and may require a period of observation to prove their transplant candidacy, hence adding to the KT evaluation time (Schaeffner et al., 2008). Lower income patients are more likely to have health issues that would require more time for investigations and/or interventions that delay the KT completion (Held et al., 1988). Medicare ESRD Program pays fully for lifelong dialysis treatment but for only up to three years of immuno-suppressive medications post-KT. However, transplanted patients have a lifelong reliance for such medications. Because lower income patients rely heavily on Medicare for their ESRD treatment (Woodward et al., 2001; Young & Gaston, 2002) and at the same time lack co-insurance, (Ayanian, Cleary, Weissman, & Epstein, 1999; Churak, 2005; Held et al., 1988), their concerns on longer-term medication affordability possibly make them require more time to contemplate the KT option. Lower income patients have poorer KT outcomes when compared to those from higher income groups (Goldfarb-Rumyantzev et al., 2006), and this likely resulted in the lower income patients having reservations on the viability of their KT option and needed more time to evaluate their treatment choice. Evidently, an amalgamation of factors combined to reduce the KT evaluation rate for lower income patients.

This study corroborates existing evidence that African Americans are also vulnerable to a lower KT evaluation completion rate (Alexander & Sehgal, 2001; Ayanian et al., 1999; Epstein et al., 2000; Myaskovsky et al., 2012; Myaskovsky et al., 2007; Patzer et al., 2012; Waterman et al., 2013). The reasons for their lower KT evaluation are many and complex and isolating them would not be possible (Gordon, 2012). A frequently held explanation is their socio-economic

characteristics such as comparatively lower income, education and health literacy (Browne, 2008; Held et al., 1988) account for this phenomenon. Similar to lower income patients, African American patients rely heavily on the Medicare ESRD Program while having no or inadequate co-insurance (Alexander & Sehgal, 2001). This could heighten their concern on their ability to maintain on life-long immune-suppressant, and dialysis would therefore appear as a more viable treatment than a KT, and this in turn reduces their participation in the KT evaluation process. Further, African Americans are more likely to experience transplant failure compared to whites (Press et al., 2005; Young & Gaston, 2002), whereas they have survival advantage over whites in dialysis treatment. Compounded with the absence of guaranteed success in KT, African Americans could prefer dialysis to KT instead. With their relative survival disadvantage in kidney transplantation, the preference of African Americans to remain on dialysis instead of taking their chance at KT should not be entirely surprising (Ayanian et al., 1999; Held et al., 1988). It must be clarified that participation in the KT evaluation does not necessarily imply patients' certainty for wanting a KT. The ambiguity African Americans face regarding KT—attributable to medical factors and the previously discussed cultural and religious beliefs—can make them less engaged in the KT evaluation process and extend their evaluation time

(Gordon, 2001; Myaskovsky et al., 2012). Perceived discrimination and medical mistrust (Myaskovsky et al., 2012) and a desire to keep the body intact have been cited (Gordon, 2001). Further as discussed earlier in the literature review, religious objection and cultural factors, such as medical mistrust and perceived racism and discrimination in the healthcare system, affect the time it takes for African Americans to complete KT evaluations and be accepted for a KT. The longer time taken by African Americans to complete KT evaluation could be an expression of

personal preference, and not necessarily indicative of the comparative socio-economic disadvantages they may face.

This study confirms existing evidence that increased age significantly reduces the chance of KT completion (Schold et al., 2011; Yuan, Bohlen, & Abbott, 2012). One speculation is that older patients need more time to reconsider if they really want a KT because increased age has been linked to a preference of maintaining the status quo in treatment (Gordon, 2001). But even if the preference for older patients is for a KT, because of their likelihood of greater illness comorbidity associated with age, they are more likely to face hindrances in completing the KT evaluations (Lenihan et al., 2013; Merkus et al., 1999). Illness comorbidity is known to hamper the KT evaluation process—a disadvantage also experienced by lower income and African American patients— (Gaylin et al., 1993). Patients with more illness comorbidity require extra medical tests or have additional medical requirements they must meet that lengthen their KT evaluation process (Yuan et al., 2012). For example, obese patients have to achieve weight reduction before they can be listed for a KT (Pham et al., 2010).

The analysis shows that race—specifically being African American—and older age have a time dependency characteristic in that their lower KT evaluation completion rate mitigated in the latter stage of the evaluation process. However, this implication should be restricted to merely a statistical interpretation. Clinically, these groups still significantly lag behind in the KT evaluation process and must be supported to help them attain a higher completion rate in order to promote equity of care.

### **5.2.2 Illness Burden**

The determined association between illness burden and Charlson Comorbidity Index is an unsurprising finding because both are related to pervasiveness of illness, albeit one is a

subjective measure and the other an objective one, respectively. It is intriguing, however, that illness comorbidity was significantly associated with KT evaluation completion time but illness burden was not. The speculation may be that because illness burden was measured at Time 1 before the study participants commenced the KT evaluation, those study participants who reported having low illness burden did not feel an urgency to complete the KT evaluation and hence took a longer time to complete it. Among these patients, those who were dialysis-dependent likely felt adequately or well-adjusted to their treatment and were taking longer to complete evaluation to give themselves more time to decide whether they really wanted a KT. Those who were pre-dialysis would likely experience low illness burden because they did not have to yet deal with the time and lifestyle constraints concomitant with a dialysis-dependent life. Further, having yet to experience the full assault of ESRD could make them feel less pressured into seeing a need for quicker KT evaluation completion in order to avoid the throes of dialysis treatment.

### **5.2.3 Social Network**

The hypothesis that a bigger social network is associated with lower KT completion time was not supported. In this study, the social network size ranged widely from 0-127, with a median of 17. To the best of my knowledge, there is no suggested network size that is considered as adequate or ideal. In the work of Cetingok, Winsett, Russell and Hathaway (2008), they made an a priori albeit arbitrary decision that a network size of 15 members was considered adequate for their study. Although the median social network size of 17 in this study is slightly above the size proposed by Cetingok et al. (2008), it must be clarified that this has no meaningful implication. This observation is a reiteration of a challenge in this field of study in that there is no objective criterion for network size adequacy. Further, when social network size is used as a measure of

social support, it assumes that the amount of help received corresponds to the size of the network, and that the presence of a social relationship implies social support. However, such assumptions can be faulty (S. Cohen & Wills, 1985; House et al., 1985; Schaefer et al., 1981). Social network size merely indicates the number of members in a person's web of relationships, and the number is not necessarily synonymous with strength of support (House et al., 1985; Schaefer et al., 1981; Tracy & Whittaker, 1990). In this study, African American's larger social network size did not accord them any evaluation completion advantage, and neither did the smaller network size of lower income and older study participants disadvantage them. This finding highlights the limited role of social network size in influencing KT evaluation completion.

More pertinent than social network size, is the examination of the composition of the social network. In the view of Browne (2008), it is the content of the social network that is relevant in affecting KT evaluation completion. A person who has members in his or her social network who is knowledgeable about kidney transplantation has the advantage of receiving informational support that could contribute to the KT evaluation process (Browne, 2008; Exley et al., 1996; K. Ladin & Hanto, 2010; Randhawa, 2005). This is because social network is the pathway through which social support and influence, including KT attitudes and beliefs, are delivered (Berkman et al., 2000; Gordon, 2001; Smith & Christakis, 2008; Uchino et al., 1996). There is another explanation why social network composition is pertinent to the completion of KT evaluation. Based on the notion of homophily in that an individual's social network is likely to consist of people similar to the individual (McPherson et al., 2001), and given that African Americans and lower income patients are known to be less knowledgeable about KT (Browne, 2008; Kazley et al., 2012; Waterman et al., 2013), and African Americans have less favorable

cultural beliefs regarding KT, the social networks of these groups of patients are likely less conducive in positively influencing them towards KT evaluation completion. Further, their social networks are likely to be similar to themselves in terms of being anemic in resources to be able to supply them with social support that would otherwise enhance their KT evaluation completion (Harknett & Hartnett, 2011).

#### **5.2.4 Perceived Social Support**

The median of perceived social support suggests a reasonably high degree of perceived social support among participants in this study. And greater social support has been found to enhance KT evaluation completion rate (Cass et al., 2003; Clark et al., 2008; Kazley et al., 2012; Steinman et al., 2001). Greater social support expands patients' time and energy resources to cope with the appointments and requirements of KT evaluation (Clark et al., 2008) Two-thirds of the study participants are dialysis-dependent, and within this group, 80% are relying on hemodialysis, which is time-consuming given its thrice-weekly treatment sessions at a dialysis facility. The presence of social support may help in coping with both the dialysis treatment and KT evaluation demands.

Outcomes from this study support the main effects model of social support, not the stress-buffering model. The main effects model posits that the presence of social support—even when one is not confronted with a stressful situation—proffers a sense of belongingness and a sense of availability support when needed, and such beliefs convey benefits to life and health in general (Pearlin, 1985; Thoits, 1982). That is, just having social support is good, irrespective if one is dealing with a stressful situation or not. Therefore, although ESRD exerts significant illness burden because of its illness impact, treatment demands and iatrogenic effects (Christensen & Ehlers, 2002; Devins et al., 1993; Gerald M Devins et al., 1990; Hagren et al., 2001; Kimmel,

2000b; Merkus et al., 1999), and participants in this study reported a high level of illness burden, social support does not buffer ESRD illness burden to facilitate the completion of KT evaluation. It is the very nature of social support that enabled and supported those with greater social support in completing their KT evaluations; the benefits of social support are not manifested only in those with higher illness burden.

In summary, the results of this study show that certain demographic groups are disadvantaged in having a lower KT evaluation rate, and these are the older patients, those with lower income and African Americans. Clinical factors, such as illness comorbidity, are also an impediment to the KT evaluation process. However, greater social support leads to better KT evaluation completion rate. The belief that social support buffers ESRD illness burden to enhance completion of KT evaluation cannot be supported in this study. Instead, social support is believed to have overall benefits, and such benefits contribute to better KT evaluation completion rate, regardless of whether the patients have a high level of illness burden or not.

### **5.3 LIMITATIONS**

The results of this study must be evaluated in the context of the study limitations. There is a lack of generalizability of this study because it was based on a single-center experience, although the race sample is representative of the national ESRD population (USRDS, 2013). There was no random selection of participants. Instead, study participants were recruited based on their voluntary participation when they presented for their first transplant clinic appointment, and this sampling bias limits the degree of population representativeness. On the other hand, this study had a high response rate of over 90 per cent, which is unusual in a clinical sample, particularly for a large one.



In this study, patients who indicated more than one race where African American was one of the races selected were counted as African American for the analysis. Although such a procedure is consistent with research practice in race and health research, and one justification is that a person who indicates “African American” in his/her race selection is likely to have experiences shared by other African Americans patients, such a manner of coding could be a limitation in this study. This is because it can be argued that if a participant has some African American origin and yet simultaneously identifies himself/herself in two categories (African American and other), it could imply that the participant does not quite identify with the African American race. Hence to categorically treat such cases as African Americans may not be accurate or correct from this perspective.

Although this study examined the size of a patient’s social network, it did not examine the productivity of the social network, that is, how helpful the social network may or may not have been. Because social networks are the conduits through which health information flows, examining social network characteristics are better at KT knowledge, attitudes and beliefs are influenced, and how they in turn affect the KT evaluation process (Browne, 2008; Cass et al., 2003; K. Ladin & Hanto, 2010; Turner & Marino, 1994; Waterman et al., 2013).

One of the strengths of utilizing a time-to-event analysis such as Cox regression is that it can take into account censored data, and such observations should be included in the analysis even though the participants did not experience the event because their time spent in the study is still informative. However, because the proportionality of hazard assumption was violated in this study, hence indicating time-dependency of the covariates such that the hazard ratios cannot be interpreted directly, this outcome limits the interpretation of the results. Nonetheless, it has been argued that while such violations arouse statistical concern, they ought to be accepted as the

norm because they reveal the reality and offer meaningful information about the data collected (Singer & Willett, 1991; Willett & Singer, 1993).

The limitations notwithstanding, this study still contributes to the literature in several ways. This is seemingly the first study that set to determine if social support buffers illness burden in time to complete KT evaluation. This study extends the current understanding on the benefits of social support in facilitating KT evaluation completion (Cass et al., 2003; Clark et al., 2008; Kazley et al., 2012; Scandling, 2005; Steinman et al., 2001). It also adds to the current data on racial and income disparities in KT completion.

#### **5.4 IMPLICATIONS FOR SOCIAL WORK PRACTICE**

The outcomes from this study suggest that patients who are older, from lower income, African American and with less social support are at risk of taking a longer time or not completing the KT evaluation, which therefore reduces their access to kidney transplantation. These patient populations are considered the vulnerable populations that the mission of social work is committed to helping (NASW, 2008). Transplant social workers are well-positioned to identify and intervene with these vulnerable groups so as to enable them to more quickly and successfully complete the KT evaluation. This section discusses interventions aimed at assisting these groups of patients.

##### **5.4.1 Tangible support**

The provision of tangible support is pertinent for helping these at-risk groups who have less tangible resource of their own, and who are less connected to resources within the healthcare system. A key role of the social worker is that of a resource broker, linking clients to necessary resources to enhance their coping (Hepworth, Rooney, Rooney, Strom-Gottfried, & Larsen,

2009). Therefore transplant social workers need to identify at-risk patients and provide them with the needed tangible support to enable them in completing the evaluation. Further, transplant social workers must explore if they may have resource adequacy concerns for the immediate period post-transplant. Such concerns if unaddressed, may induce patients' doubts if KT is a feasible treatment option and affect their commitment to complete the evaluation process. For example, patients needing transportation aid to the transplant center during the KT evaluation phase are likely to require similar support post-transplant for their medical follow-up. Assistance that provides for caregivers, babysitting or domestic help during the recuperative phase, and transportation aid to the transplant center are examples of tangible support that a transplant social worker could offer. While the provision of such services would entail costs, a longer term and societal perspective would conclude that the cost-savings of KT over chronic dialysis for the treatment of ESRD would appear to justify such costs (Yen et al., 2004). Further, targeting and enabling these vulnerable populations are integral in addressing healthcare inequities (Nelson, 2002; People, Health, & Services, 2011).

#### **5.4.2 KT evaluation services**

Interventions to increase KT evaluation completion rates must also target the delivery of KT evaluation services. A potential consideration is the use of fast-track KT evaluation whereby required testing are located at a single setting and conducted over fewer days that reduces patients' navigation of the many KT evaluation steps (Myaskovsky et al., 2012). Increased engagement between transplant service personnel and patients undergoing KT evaluations who have been identified as at-risk for longer KT evaluation time will help increase the likelihood that the patients would adhere to the required testing (Myaskovsky et al., 2012). Further it

provides the avenue for patients to discuss any concerns or difficulties they may be encountering regarding the pursuit of KT.

Another possible intervention strategy is to introduce an onsite KT education class before potential candidates commence their medical KT evaluation assessment. Mandatory attendance in such an education session has reportedly improved the KT evaluation completion rate, particularly among African Americans and the lower income groups because participants benefited from patient education—a source of appraisal or informational support—and increased engagement with transplant professionals to address their questions and concerns (Patzner et al., 2012). For example, the belief that one would not pass the KT evaluation tests and fears about KT are known impediments to the process, and a KT education class is a platform for disseminating correct information and correcting erroneous one (Alexander & Sehgal, 2001; Kazley et al., 2012; Myaskovsky et al., 2012; Sullivan et al., 2012). Having healthy KT recipients present at such education sessions can debunk myths and address fears that some KT evaluation patients may have regarding KT (Kazley et al., 2012). Increasing informational support to patients undergoing KT evaluation is important because it is known to increase KT evaluation completion rate (Waterman et al., 2013). Relying on transplant navigators— kidney transplant recipients trained to support patients through the KT evaluation process— is another intervention consideration (Schold et al., 2011). Because of their experience of ESRD and the KT evaluation process, transplant navigators can provide empathic understanding that transplant professional cannot (Thoits, 1982). This is an added benefit in utilizing them to enhance patients' KT evaluation completion rate. Because race differences exist, enhancing transplant personnel's cultural sensitivity to patients undergoing KT evaluation is recommended. This is particularly relevant for African American patients whose beliefs and attitudes concerning

kidney transplantation are known to affect their KT decisions and evaluation process (Klassen et al., 2002; Myaskovsky et al., 2012).

Transplant social workers can conduct support groups for patients undergoing KT evaluation and those who are on the KT waitlist as an avenue for appraisal and emotional support (Olbrisch et al., 2002). Including the latter in the support groups has an advantage in that they can share from their KT evaluation experience to encourage and guide those who are still undergoing the process. Patients' families can also be invited to participate in such support groups since such sessions can be an outreach platform to those who may require support as caregivers (Skotzko, et al., 2001). At the same time, it potentially engages families in bolstering their support for the patients. Additionally, intervening with families acknowledges the interdependency between the individual patient and his/her family system (Boise, Heagerly & Eskenazi, 1996). Because hemodialysis is the predominant dialysis treatment of choice, and it involves thrice-weekly aggregating some 12 hours, the dialysis center is a strategically located platform to reach out to ESRD patients regarding kidney transplantation. Healthcare providers, including social workers, at dialysis centers can be more involved in helping patients complete their KT evaluation (W. Wolfe & Toomey, 2004).

### **5.4.3 Implications for medical social work**

Among transplant professionals, social workers are likely the only ones who adopt a systems perspective that includes an examination of the patient's support network. Social workers ought to leverage on this perspective and assess patients' social network for quantity and quality of social support that may facilitate KT evaluation completion (Olbrisch et al., 2002). The eco-map has been used in social work practice to examine the client's systems in the environment. Its assessment focuses on the individual's family system and other systems, including if

relationships are strong or conflictual (Tracy & Whittaker, 1990). Significant relationships that are negative can potentially impede while positive relationships enhance the KT evaluation process. A variation of eco-map, a social network map is more informative than an eco-map because in addition to the map that visually displays the network of relationships an individual is linked to, it uses a grid to record supportive and non-supportive functions and other pertinent characteristics in the social network that can affect the individual's functioning (Tracy & Whittaker, 1990). The use of a social network map can be extended to transplant social work for evaluating both the negative and positive elements in the patient's social network that may affect the KT evaluation process. For instance, a spouse who is unsupportive of the patient's wish to pursue KT may discourage or hinder the patient's advancement in the KT evaluation steps. Besides working directly with the spouse to address his/her lack of support for patient's interest in KT, the social worker can utilize the social network map to identify other target members in the patient's social network for intervention. Identifying negative aspects of social relationships is important to introducing appropriate interventions (Lewis, Winsett, Cetingok, Martin, & Hathaway, 2000; Lincoln, 2000).

In summary, interventions to promote completion of KT evaluation must be targeted and adopt a multi-faceted approach that tackle service users as well as service providers, and situated along various points in the KT evaluation process (Alexander & Sehgal, 2001; Clark et al., 2008). Enhancing patients' social networks so that they can be more conducive in delivering social support is integral to improving KT evaluation completion rate, as evidenced by this study. Transplant professionals and transplant services should not overlook that they are part of the patient's network and have vital roles to play in providing various forms of support: informational, emotional and tangible. Aiding patients in completing KT evaluations will bring

them a step closer to accessing kidney transplantation—the optimal ESRD treatment. At the same time, transplant social workers should not narrowly focus on patients’ prompt completion of the KT evaluation as an intervention objective. They should also ensure that patients who are being evaluated for KT are adequately certain of their treatment choice, and work through the patients’ ambivalence, if any, by delivering emotional and informational support. Should a patient require more time to reconsider KT, or changes his or her mind regarding KT, these options must be respected as part of upholding the patient’s autonomy and informed consent (Buchanan, 1989; Richards, 2012). By taking steps to remove KT evaluation barriers and increase the social support of vulnerable patient groups, transplant social workers are promoting the well-being of the patients, engaging in client advocacy, and upholding the values of distributive and social justice.

## **5.5 IMPLICATIONS FOR FUTURE RESEARCH**

To more clearly explain the role of social networks in influencing time to complete KT evaluation, future research should examine social network composition in addition to social network size. An analysis of a social network that considers whether its members possess KT knowledge, and how they influence the patients in KT decisions and evaluation will shed more light on the role of social network in the completion of KT evaluation (Arthur, 2002; Browne, 2008; Gordon, 2001; Holley et al., 1996; K. Ladin & Hanto, 2010; Weng et al., 2005). Because social networks that offer inadequate social support are risk factors for KT-related processes and outcomes, and because demographically-related differences in social networks can affect patients’ access to treatment information, an examination of the composition of patient’s social network could help the understanding of what social network types accord KT evaluation

advantage to patients (Cass et al., 2003; House et al., 1985; Keren Ladin et al., 2009; Turner & Marino, 1994; Weng et al., 2005). Future consideration for a mixed-method study involving patient interviews can strengthen the conclusions reached in this quantitative study. A qualitative study to explore more deeply the impediments and facilitators patients encounter as they advance through the KT evaluation process would also contribute to the current body of knowledge (Kazley et al., 2012). Further, comparing interview response of study participants who completed the KT evaluation within a specified time frame and those who did not, and with a focus on social network composition and actual social support received that expedited KT evaluation completion can better illuminate the roles served by the structural and functional aspects of social support (Pearlin, 1985).

An intervention study could be a future research consideration. Comparisons of KT evaluation completion rate can be made between a control group of patients who did not receive interventions aimed at increasing social support and an intervention group who received social support. This will elucidate the influence of social support and the effectiveness of social support interventions. Results from such a study are a form of program evaluation that can advise on service improvements and service development.

A similar study that includes more variables could provide more insight on the factors that interact with social support in influencing KT evaluation completion. The types of health insurance that patients have can affect KT evaluation completion rate. Although the National ESRD program pays for dialysis treatment and KT, an existing policy gap which limits Medicare coverage for the lifelong requirement of post-transplant immuno-suppressant mediations to the first three years is particularly detrimental for low income and minority race patients (Woodward et al., 2001). African American and lower income patients rely heavily on Medicare for their



ESRD treatment (Woodward et al., 2001; Young & Gaston, 2002). Coupled with a lack of co-insurance, they can become deterred from pursuing kidney transplantation (Held et al., 1988; Ayanian et al., 1999; Churak, 2005). Inadequate health insurance lowers personal resources, and implies a likely need for more social support, and in particular, tangible support. The links between health insurance, social support needs, and KT evaluation completion deserve more investigation because such knowledge has implications on services and policies. Another variable for consideration is dialysis status. Weng and colleagues (2005) produced the only known study investigating how pre-dialysis and dialysis-dependent patients differed on KT evaluation completion rate, but found no difference. Patients on CAPD treatment and those on hemodialysis treatment may differ in their perceived illness burden because of different treatment demands and iatrogenic effects. In contrast, pre-dialysis patients are spared the time constraints associated with dialysis treatment and are likely to have lower illness burden. We need to expand the current body of knowledge on how dialysis status may affect KT evaluation completion. Particularly if pre-dialysis status is associated with reduced illness burden and lower KT evaluation time, there is an implication for encouraging patients to consider pre-emptive KT or undergo KT evaluation before they become dialysis-dependent.

In short, we have to continue to expand our knowledge on the factors that affect patients' KT evaluation completion through social research. Knowledge gleaned from such studies can aid us to more effectively intervene and provide support in helping patients complete KT evaluation, with a particular focus on the vulnerable groups, namely the elderly, low income and minority race. Evidenced-based interventions have the potential of contributing to better utilization of societal resources.

## 5.6 CONCLUSION

This prospective cohort study examined the influence of social support in ameliorating illness burden to facilitate completion of KT evaluation in a university hospital transplant center setting. Results suggest that illness burden did not affect time to complete KT evaluation, and that social support had no buffering effect on illness burden to complete KT evaluation. However, the presence of social support positively enhanced KT evaluation completion in that greater social support improved KT completion rates. Participants with higher income also were advantaged in requiring less time to complete KT evaluation. Race differences exist in KT evaluation completion time in that African Americans had a significantly lower KT completion rate compared to whites. However, there was a time-varying characteristic demonstrated by African Americans, older patients and higher social support level on the KT evaluation completion rate such that their lower completion rate did not persist throughout the study.

This study will contribute to transplant professionals in targeting patients groups who are less likely to complete KT evaluations and providing them social support in helping them advance through the process.

## **APPENDIX A**

1. Questions on number potential living donor as an estimate for social network size
2. Interpersonal Support Evaluation List (ISEL-12)
3. Burden of Kidney Disease Subscale

**1. QUESTIONS ON NUMBER POTENTIAL LIVING DONOR AS AN ESTIMATE FOR SOCIAL NETWORK SIZE**

1. List the number of living parents you have between the ages of 18 and 75.
2. List the number of living children you have between the ages of 18 and 75.
3. List the number of living brothers or sisters you have between the ages of 18 and 75
4. List the number of living aunts, uncles, or cousins you have (that you feel close to, even if they're not your blood relative) between the ages of 18 and 75.
5. List the number of living in-laws you have (anyone in your spouse's family that you feel close to) between the ages of 18 and 75.
6. List the number of close friends you have between the ages of 18 and 75 (meaning people that you feel at ease with, can talk to about private matters, and can call on for help).

## 2. INTERPERSONAL SUPPORT EVALUATION LIST (ISEL-12)

	Definitely False	Probably False	Probably True	Definitely True
1. If I wanted to go on a trip for a day (for example, to the country or mountains), I would have a hard time finding someone to go with me.	1	2	3	4
2. I feel that there is no one I can share my most private worries and fears with.	1	2	3	4
3. If I were sick, I could easily find someone to help me with my daily chores.	1	2	3	4
4. There is someone I can turn to for advice about handling problems with my family.	1	2	3	4
5. If I decide one afternoon that I would like to go to a movie that evening, I could easily find someone to go with me.	1	2	3	4
6. When I need suggestions on how to deal with a personal problem, I know someone I can turn to.	1	2	3	4
7. I don't often get invited to do things with others.	1	2	3	4

Appendix A2 (Continued)

	Definitely False	Probably False	Probably True	Definitely True
8. If I had to go out of town for a few weeks, it would be difficult to find someone who would look after my house or apartment (the plants, pets, garden, etc.).	1	2	3	4
9. If I wanted to have lunch with someone, I could easily find someone to join me.	1	2	3	4
10. If I was stranded 10 miles from home, there is someone I could call who could come and get me,	1	2	3	4
11. If a family crisis arose, it would be difficult to find someone who could give me good advice about how to handle it.	1	2	3	4
12. If I needed some help in moving to a new house or apartment, I would have a hard time finding someone to help me.	1	2	3	4

### 3. BURDEN OF KIDNEY DISEASE SUBSCALE

	Definitely False	Probably False	Probably True	Definitely True	Definitel y False
1. My kidney disease interferes with my life.	1	2	3	4	5
2. Too much of my time is spent dealing with my kidney disease.	1	2	3	4	5
3. I feel frustrated dealing with my kidney disease.	1	2	3	4	5

## APPENDIX B

### *Cross-tabulation on Sex, Race and Income across Illness Burden, Social Network Size and Perceived Social Support Quartiles*

Variables	N	Illness Burden				Social Support							
		Q1	Q 2	Q3	Q4	Social Network Size				Perceived Social Support			
		Q1	Q 2	Q3	Q4	Q1	Q 2	Q3	Q4	Q1	Q 2	Q3	Q4
Sex													
Male	700	147	178	188	187	164	148	210	178	175	200	148	177
Female	430	111	99	92	128	107	116	109	98	94	117	110	109
Total	1030	$\chi^2 (6) = 7.43, p = .059$				$\chi^2 (3) = 6.92, p = .075$				$\chi^2 (3) = 3.58, p = .310$			
Race													
White	776	179	187	194	216	195	193	221	167	163	219	183	211
*Af. Am.	260	62	71	60	67	60	45	74	81	75	71	58	56
Other	94	17	19	26	32	16	26	24	28	31	27	17	19
Total	1130	$\chi^2 (6) = 4.97, p = .546$				$\chi^2 (6) = 16.86, p = .010$				$\chi^2 (6) = 13.39, p = .037$			
Income (\$)													
< 25,000	526					148					150	107	
		105	116	137	168		108	140	130	156			113
25,001-50,000	270					61	71	73	65	56	70	71	73
> 50,000	276	62	71	74	63					39	83	68	86
Total	*1072	75	76	58	67	44	72	92	68	39	83	68	86
		$\chi^2 (6) = 18.38, p = .005$				$\chi^2 (6) = 18.38, p = .005$				$\chi^2 (6) = 30.89, p < .001$			

Quartile 1 = Q1, Q2 = Quartile 2, Q3= Quartile 3, Q4= Quartile 4.

\*Af. Am. denotes African American.

\*\*There are 58 missing values.



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