THE MULTIDIMENSIONAL KIDNEY TRANSPLANT SELF-MANAGEMENT SCALE: DEVELOPMENT AND PSYCHOMETRIC TESTING

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DEDICATION

I dedicate this research to my former chair, Dr. Janet Welch, who patiently guided and cultivated me from a novice to a researcher.

This work also is dedicated to my parents, Wen-Nan Chung and Shin-Yi Hsieh who supported me throughout this journey.

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THE MULTIDIMENSIONAL KIDNEY TRANSPLANT SELF-MANAGEMENT SCALE: DEVELOPMENT AND PSYCHOMETRIC TESTING

Poor long-term kidney transplant outcomes are a significant problem in the U.S. Interventions must focus on preserving allograft function by managing modifiable risk factors. An instrument capable of identifying problems with post-kidney transplant self-management behaviors may enable the design and testing of self-management interventions. This study's purpose was to test the psychometric properties of the new Kidney Transplant Self-Management Scale (KT–SM). The Zimmerman framework adapted for kidney transplant self-management guided the cross-sectional study. A total of 153 kidney recipients recruited from Facebook® completed the Self-Efficacy for Managing Chronic Disease (SEMCD), Patient Activation Measure (PAM), Kidney Transplant Questionnaire (KTQ), and KT–SM Scale instruments via a REDCap® survey. Most participants were female (65%), White (81.7%), and middle-aged (M = 46.7; SD = 12.4 years) with a history of dialysis (73%) and received a kidney transplant an average of 6.58 years previous (SD = 6.7). Exploratory factor analysis results supported the 16-item KT–SM Scale as a multidimensional scale with five domains with loadings ranging between .39 and .89: medication adherence, protecting kidney, cardiovascular risk reduction, ownership, and skin cancer prevention. Internal consistency reliability for the total scale (Cronbach's α = .84) and five domains ranged from .71 to .83. The total and domains were positively correlated, ranging from r = .51 to .76, p = .01. Criterion-related validity was evidenced by significant correlations of KT–SM and domains with SEMCD (r =.22 to .53, p = .01), PAM (r = .31 to .52, p = .01), and the

overall KTQ (r = .20 to .32, p = .01) except for one KT–SM domain: protecting kidney. Construct validity was evaluated using multivariate regression analysis. The linear combination of age, patient activation, and self-efficacy explained 45% of the variance in KT–SM behaviors; 47% of the variance in KTQ (measuring quality of life) was predicted by age, comorbidity, and self-efficacy. These findings provide beginning evidence of reliability and validity for the newly developed KT–SM scale. Instruments like this may provide a means to capture the self-management behaviors of the kidney transplant population, which is critical for future work on interventions.

Eileen Hacker, PhD, RN, APN, AOCN, FAAN, Chair

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

Abbreviation	Term
CCI	Charlson Comorbidity Index
CV	Cardiovascular
CVI	Content Validity Index
EFA	Exploratory Factor Analysis
ESRD	End-stage Renal Disease
HRQoL	Health-related Quality of Life
IS	Immunosuppressive
KMO	Kaiser-Meyer-Olkin
KT	Kidney Transplant
KTQ-25	Kidney Transplant Questionnaire
KT-SM	Kidney Transplant Self-Management Scale
PAF	Principal Axis Factoring
PAM	Patient Activation Measure
PI	Primary Investigator
SEMCD	Self-Efficacy for Managing Chronic Disease
SF-36	Medical Outcomes Study Short Form-36
SCQ	Self-Administered Comorbidity Questionnaire
SM	Self-management

CHAPTER ONE

THE NATURE OF THE STUDY

Short-term kidney transplant (KT) outcomes have improved because of advances in surgical techniques and the introduction of more potent immunosuppressive (IS) medications. Improved outcomes include abatement in acute transplanted kidney rejection episodes and increased first-year allograft survival rates of 92%–95% (Legendre, Canaud, & Martinez, 2014; Sherston, Carroll, Harden, & Wood, 2014; Wekerle, Segev, Lechler, & Oberbauer, 2017). In contrast, long-term post-KT outcomes remain a significant problem (Levy et al., 2014; Napoli et al., 2014; Sherston et al., 2014; Stegall, Gaston, Cosio, & Matas, 2015; Wekerle et al., 2017). In a retrospective study of data from the United Network for Organ Sharing (UNOS) and the University of California Los Angeles KT registries from 1969 to 2005, the reported 10-year graft survival rates show miniscule improvement from 1985 to 2005 despite the introduction of new IS agents (Kaneku & Terasaki, 2006). Similarly, Gondos, Döhler, Brenner, and Opelz (2013) examined first-, fifth-, and tenth-year graft survival between the United States and Europe, employing data for the years 2005 to 2008 from the UNOS/Organ Procurement and Transplantation and from European transplant centers. Gondos et al. found that the overall first-year graft survival rates were almost equal between the United States and Europe. However, the overall 5- and 10-year graft survival rates in U.S. were 67% and 43% compared to Europeans' 77% and 56%, respectively. Legendre et al. (2014) arrived at a similar conclusion that allograft function loss and mortality increase significantly five years' post-transplant. Factors contributing to poor long-term transplant

outcomes are categorized as donor factors, recipient factors, and immunological factors (Cangro, 2014; Legendre et al., 2014; Wekerle et al., 2017).

Donor factors refer to the quality of the kidney. There are two types of kidney donor transplants: living and deceased. Both types of kidney recipients have better long-term outcomes when compared to people receiving long-term dialysis, though living-donor KT patients have longer graft survival and lower mortality than deceased-donor KT recipients (Englum et al., 2015; Hart et al., 2017). Another donor-related factor is the increasing use of extended-criteria donor (ECD) kidneys worldwide. A donor is considered ECD if he or she is more than 60 years of age or between 50 and 60 years but with two or more of the following risk factors: hypertension, diabetes mellitus, creatinine greater than 1.5 mg/dL, or death due to stroke (Barba et al., 2013; Zens et al., 2018). The use of ECD for KT permits more end-stage renal failure patients (including older patients) to have a KT, but this practice is not without risk. The recipients of ECD have higher mortality rates, more cardiovascular (CV) episodes, and poorer allograft function compared to standard criteria donor kidney recipients (Barba et al., 2013; Legendre et al., 2014; Palkoci, Vojtko, Fialová, Osinová, & Lajčiaková, 2018).

Recipient factors including age, race, pre-transplant dialysis duration, obesity/weight gain, and CV disease prior to the transplant have been linked to early graft loss and high mortality rates (Hellegering et al., 2013; Hoogeveen et al., 2011). Although older recipients have lower long-term graft survival rates as compared to younger recipients, they still have longer life expectancy, lower mortality, and better quality of life than dialysis patients (Englum et al., 2015; Knoll, 2013; Matas, et al., 2015). African

Americans have higher acute kidney rejection rates and chronic allograft failure than other ethnic groups due to immunological factors such as a strong immune response or non-adherence to prescribed treatments and non-immunological factors including higher CV risk factors and low socioeconomic status (Cole, Johnson, Egede, Baliga, & Taber, 2018; Gralla, Le, Cooper, & Wiseman, 2014; Narayanan et al., 2014). Another important recipient factor is duration of dialysis prior to KT. Longer duration of pre-transplant dialysis is associated with worse allograft survival and patient survival (McAdams-DeMarco et al., 2017; Ramesh Prasad, Ruzicka, Burns, Tobe, & Lebel, 2009; Remport et al., 2011; Smail et al., 2013); the longer patients remain on dialysis, the higher these risks become. Late graft loss and premature death with a functioning graft is linked to CV disease; experts estimate that CV disease cause 30%–55% of deaths of KT recipients (Carpenter et al., 2012; Helanterä, Räihä, Finne, & Lempinen, 2018). Pre-transplant obesity also is associated with poor kidney function as well as being a risk factor for CV disease. Furthermore, first-year post-KT weight gain is a stronger predictor of graft loss and mortality than pre-transplant obesity (Hoogeveen et al., 2011; Viscido et al., 2018). Lack of exercise, increased appetite, side effects from IS medication, and no longer being on food restrictions are common reasons for excessive weight gain (Aksoy, 2016; Ryan et al., 2014). Cashion and colleagues estimated that KT recipients gain 11 to 22 pounds after transplant; weight gain of 10%–35% in the first year following transplant also was reported (Cashion et al., 2014). First-year post-KT weight gain is positively correlated with post-KT hypertension, new-onset diabetes after transplant, and dyslipidemia; each of these conditions is also a CV risk factor (Viscido et al., 2018).

Immunological factors also have an effect. Research findings associate long-term use of IS medications with side effects and risks such as increased cancer risk, CV disease, infections, nephrotoxicity, new-onset diabetes after transplantation, obesity, and osteoporosis even though IS medications effectively decrease kidney rejection (Alshayeb, Josephson, & Sprague, 2013; Heldal et al., 2018; Sarno, Muscogiuri, & De Rosa, 2012). All these side effects and risks link to graft loss and mortality (Pasha, Alijanpour, Khafri, Basim, & Afshang, 2017). Another important immunological factor is IS medication non-adherence (Maw, 2014; Nankivell & Kuypers, 2011), which accounts for 32%–36% of graft loss (Butler, Roderick, Mullee, Mason, & Peveler, 2004; Maw, 2014). Reports estimate that 22%–35% of KT recipients are non-adherent to IS medications (Russell et al., 2010; Scheel et al., 2018). Transplant rejection rates in patients with poor adherence are seven times higher than for those who are adherent (Burkhalter et al., 2014; Scheel et al., 2018).

These three factors (donor factors, recipient factors, and immunological factors) contribute to poor long-term transplant outcomes. However, not all these factors are modifiable. Risk factors such as extended criteria donor kidney use, older age, gender, ethnicity, and IS treatment regimens are not amenable to intervention. To improve long-term KT outcomes, interventions need to focus on preserving the transplanted allograft function as long as possible by managing modifiable factors including CV risk reduction, infection prophylaxis, skin cancer prevention, and IS medication adherence (Chadban, 2008; Maw, 2014; Jamieson et al., 2016).

Problem Statement

After transplant, each KT recipient experiences a complex situation. Recipients are responsible for lifelong, day-to-day self-management (SM) tasks including adherence to IS treatment regimens; surveillance of allograft function; infection prophylaxis; skin cancer precautions; healthy lifestyle maintenance including exercise, proper diet, and weight management; and sound decision-making on seeking care (Jamieson et al., 2016; Kasiske et al., 2009; Ndemera & Bhengu, 2017; Urstad, Andersen, Øyen, Moum, & Wahl, 2011; Weng et al., 2013). However, few studies examined the effectiveness of discharge education used to improve post-transplant SM (Urstad et al., 2011). Additionally, current post-KT discharge education may not enable patients to manage complex post-transplant SM tasks (Haspeslagh et al., 2013; Hwang, & Yi, 2015; Urstad, Wahl, Andersen, Øyen, & Fagermoen, 2012). Researchers indicate that KT recipients may not be trained sufficiently to develop SM skills. Most intervention programs focus mainly on improving medication adherence; knowledge regarding kidney allograft monitoring and maintaining a healthy lifestyle have not been addressed (Urstad et al., 2012).

There are three instruments related to KT SM (Kosaka et al., 2013; Schmid-Mohler, Schäfer-Keller, Frei, Frei, & Spirig, 2014; Weng, Dai, Huang, & Chiang, 2010). One limitation of these instruments is that their reliability or construct validity analyses are low or not reported, indicating they may not be reliable or valid. Lack of theoretical foundation and inadequate definitions of concepts related to SM are concerns as well. Theory plays a vital role in instrument development because it helps researchers to think clearly about what to include in the measure and how to

interpret the results (DeVellis, 2012). Moreover, carefully defining constructs of interest conceptually and operationally is the initial step of instrument development because many constructs are not directly observable and might be composed of multiple domains (Johnson & Morgan, 2016). An instrument that has no guiding theory and fails to define the constructs of interest is highly likely to have poor construct validity (Pett, Lackey, & Sullivan, 2003). Wording of the questionnaire is another concern. Many of the items on existing surveys are double- or triple-barreled questions—that is, questions may have two or three different answers, but the respondent is forced to provide one only. Lastly, lack of generalizability due to lifestyle, food preference, and cultural differences between Western and Asian countries make these instruments difficult to apply to U.S. KT recipients. For example, some questions include, "I eat small dried fish to help boost bone health," "I wear a mask all the time if I am in a crowded, public place," and "I eat a non-greasy bland diet and avoid spicy food." These questions may not be relevant or even understood by people who are not used to the referenced practices. Therefore, an instrument capable of identifying problems with post-transplant SM behaviors specifically designed for U.S. KT recipients will set the stage for the design and testing of SM interventions.

Purpose

This study's purpose was to test the reliability and validity of a newly developed KT-SM scale among adult KT recipients aged 18 years and older. The conceptual framework used to guide the study was adapted from Zimmerman and Young's SM framework (see Figure A-1 for permission). The adapted framework incorporates Bandura's concept of self-efficacy (1998) and the patient activation model developed by

Hibbard and colleagues (Hibbard, Mahoney, Stockard, & Tusler, 2005; Hibbard, Stockard, Mahoney, & Tusler, 2004). Correlations among variables including self-efficacy, patient activation, post-transplant SM, and the outcome health-related quality of life (HRQoL) was used to evaluate the psychometric properties of the newly developed KT-SM scale.

Specific Aims and Hypotheses

Aim 1: Examine the content validity of the Kidney Transplant Self-Management (KT-SM) scale.

H_1: The KT-SM scale will demonstrate evidence of a content validity index (CVI) of 0.9 or greater for individual items and for the overall scale based on a review by four content experts of construct definition, item relevance, wording clarity, and item appropriateness.

Aim 2: Estimate the reliability of a new instrument, the KT-SM scale, among adult KT recipients.

H_2: The KT-SM scale will have adequate internal consistency coefficient as evidenced by corrected item-to-total correlations, mean inter-item correlations of greater than or equal to .30, and Cronbach's alpha greater than or equal to .70 among KT recipients aged 18 or greater.

Aim 3: Estimate dimensionality of the KT-SM scale through exploratory factor analysis (EFA).

H_3: The EFA results will support that the KT-SM scale is a multidimensional scale with more than one factor extracted, and items within each factor will have factor loading values greater or equal to .40.

Aim 4: Estimate construct validity of the KT-SM scale guided by the conceptual model by exploring relationships between the KT-SM scale and the Self-Efficacy for Managing Chronic Disease (SEMCD) scale, the Patient Activation Measure (PAM), and the Kidney Transplant Questionnaire (KTQ-25).

H_4: Controlling for demographic and clinical variables, a significant amount of variance in the KT-SM scale will be explained by self-efficacy and patient activation.

H_5: Controlling for demographic and clinical variables, a significant amount of variance in HRQoL will be explained by self-efficacy, patient activation, and KT-SM behavior.

H_6: Criterion-related validity will be supported as the 16-item KT-SM total scale and five domain scales are statistically significantly correlated with the PAM-13, SEMCD, and KTQ-25 and 5 subscales.

Framework

The conceptual framework that guided this study was adapted from Dr. Lani Zimmerman's unpublished work (2012). The theoretical foundation of the framework consisted of Bandura's social cognitive theory, the concept of self-efficacy, and patient activation theory (Hibbard et al., 2005). The adapted KT-SM framework depicts hypothesized relationships among antecedents/risk factors; mediating variables including patient activation level, self-efficacy, and SM behavior; and the outcome of HRQoL, as shown in Figure 1.

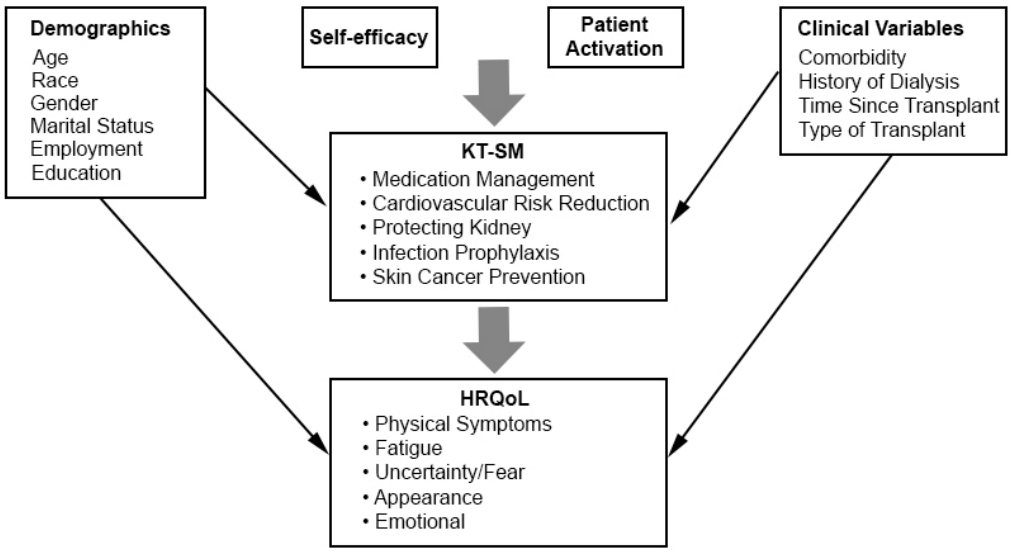

Figure 1. KT-SM Framework. Adapted from Zimmerman & Young Model. Used with permission (see Appendix A).

The antecedents/risk factors are hypothesized to be associated with patient activation level, self-efficacy, SM behavior, and HRQoL. In this study, the antecedents/risk factors were used to describe characteristics of the study population.

Antecedents (Risk Factors)

There are few studies of post-KT SM itself, but based on a broad review of KT-related studies, the antecedents and risk factors associated with is regimen non-adherence and adverse clinical outcomes can be put into two categories:

1. Demographic characteristics such as age, race, gender, marital status, employment, and education level (Chisholm-Burns, Erickson, 2012; Cole et al., 2018; Ruppar & Russell, 2009; Schaeffner, Mehta, & Winkelmayer, 2008; Woodward et al., 2008).
2. Clinical variables including comorbidities, long-term dialysis prior to transplant, time since transplant, and type of transplant (Aksoy, 2016; Lam

et al., 2017; Legendre et al., 2014; Lim, Johnson, Hawley, Pascoe, & Wong, 2018; Szeifert et al., 2010).

Mediators: Post-KT SM, Patient Activation, & Self-Efficacy

Post-KT SM. SM has been studied widely in chronic diseases such as asthma, diabetes, heart disease, mental health, lung disease, and arthritis. Efficacious SM is associated with improved long-term outcomes, including better HRQoL, engagement in self-care behaviors, fewer emergency room visits, and lower medical costs (Ditewig, Blok, Havers, & van Veenendaal, 2010; Haines, Coppa, Harris, Wisniveski, & Lin, 2018; Redman, 2007, 2009). Previous studies have shown that SM behaviors can be promoted by increasing a patient's perceived self-efficacy (Harrington, Carter-Templeton, & Appel, 2017; King et al., 2010; Kuwaiti, Ghadami, & Yousefi, 2017; Wang et al., 2017; Weng et al., 2010) and giving tailored education based on an individual's activation levels (Hibbard & Greene, 2013; Hibbard, Greene, Sacks, Overton, & Parrotta, 2017; Mosen et al., 2007).

Patient activation. Judith Hibbard and colleagues (2005) developed the concept of patient activation. Knowledge, skills, and confidence are the essential components that enable people to self-manage a chronic condition successfully. Hibbard and colleagues (2004) posited that activation level is developmental and can be increased with tailored educational interventions based on individuals' confidence, skill, and knowledge levels. In past studies, patients with a high level of activation were found to be more likely to perform health-related behaviors including self-managing behaviors, maintaining a healthy lifestyle, and seeking health information regarding their own care (Bilello et al., 2018; Hibbard et al., 2017; Nijman, Hendriks, Brabers, de Jong, & Rademakers, 2014;

Remmers et al., 2009; Ryvicker et al., 2013; Shively et al., 2013). Moreover, researchers have found that highly activated individuals are more likely to have better health outcomes such as success in controlling diabetic HgbA1C, fewer hospitalizations, and better health resource utilization (Bilello et al., 2018; Greene & Hibbard, 2012; Hibbard et al., 2004; Mitchell et al., 2014). From a psychological aspect, Magnezi, Glasser, Shalev, Sheiber, and Reuveni (2014) found that highly activated patients reported better HRQoL and fewer depressive symptom.

Self-efficacy. In social cognitive theory, self-efficacy is defined as confidence in one's own competence and ability to successfully perform a given task and reach the desired goal (Bandura, 1997; Bodenheimer, Lorig, Holman, Grumbach, 2002). Perceived self-efficacy affects various aspects of human functioning including behavior change, effort and engagement, thought process, and emotional response (Bandura, 1994). In addition, the strength of perceived self-efficacy contributes to skill building and development; the development of essential skills is hindered and impeded when people have low self-efficacy but continues to grow in people with high self-efficacy (Bandura, 1994; Pajares, 2002).

In the adapted KT-SM framework, self-efficacy is a mediator. Previous studies have confirmed positive correlations among self-efficacy, SM behavior, and HRQoL (Harrington et al., 2017; Jones & Riazi, 2011; McAuley et al., 2006; Motl, McAuley, Snook, & Gliottoni, 2009; Sarkar, Fisher, & Schillinger, 2006; Weng et al., 2010). Although there is insufficient evidence for a direct association/effect between self-efficacy and patient activation, these two variables have positive correlations with

SM and HRQoL. Therefore, in the KT-SM framework, self-efficacy is hypothesized to be associated with post-KT SM behavior, patient activation, and HRQoL.

Outcome: HRQoL

Several studies have recognized HRQoL as an important post-transplant outcome measure (Fujisawa et al., 2000; Kumnig et al., 2014; Prihodova et al., 2014; Weber et al., 2014; Zhang et al., 2017). Clinical and psychological risk factors associated with mortality and graft loss have been found to be associated with HRQoL in KT recipients and include depression, age, unemployment, immunosuppressant side effects, limited physical function, diabetes, CV disease, serum level of creatinine, and glomerular filtration rate (Fujisawa et al., 2000; Griva, Davenport & Newman, 2013; Molnar-Varga et al., 2011; Ortiz et al., 2014; Prihodova et al., 2014). Researchers have also found that KT recipients' perceived HRQoL can be used to predict long-term mortality and graft loss risk factors (Griva et al., 2013).

Conceptual and Operational Definitions

Independent Variables

Demographic factors. Demographics are the characteristics of the study population, including age, race, gender, marital status, and education (Kane & Radosevich, 2010). The primary investigator (PI) collected demographic data using patient survey form (see Appendix B) to describe the sample and to examine if poor SM behaviors, low self-efficacy, low patient activation levels, and poor HRQoL are associated with certain demographic characteristics. This self-administered, categorical, nominal, and open-ended questionnaire collected: gender (dichotomous response), age

(open-ended question), and other information such as race, marital status, employment status, and education (categorical response).

Clinical factors. The investigator collected biological and physiological clinical factors such as time since transplant, pre-transplant dialysis, and type of transplant using a self-reported medical history review developed for this study (see Appendix C). Time since transplant and years of pre-transplant dialysis were collected using open-ended questions. Categorical response options were offered for type of transplant.

Comorbidities. Comorbidities refer to one or more chronic diseases that coexist with the index disease. The comorbidities could be post-KT-related or pre-existing chronic disease (Hollisaaz et al., 2007; Valderas, Starfield, Sibbald, Salisbury, & Roland, 2009). The investigator collected comorbidity information was using the Charlson Comorbidity Index (CCI; Charlson, Pompei, Ales, & MacKenzie, 1987). The CCI has been validated in several populations including dialysis patients (Beddhu, Bruns, Saul, Seddon, & Zeidel, 2000; Cho et al., 2017; Hall, Luciano, Pieper, & Colón-Emeric, 2018) and KT recipients (Hollisaaz et al., 2007; Jassal, Schaubel, & Fenton, 2005; Levine, Schuler, & Gourishankar, 2017; Machnicki et al., 2011) for predicting long-term outcomes including graft survival, mortality, healthcare resource use, and HRQoL (Hollisaaz et al., 2007; Jassal et al., 2005; Wu et al., 2005). Traditionally, CCI is calculated based on patient medical record and administration data collected by trained researchers or professionals. This study collected data was using a web-based survey—the investigator used a questionnaire version of the CCI developed by Katz and colleagues (1996) and validated in multiple studies (Habbous et al., 2013; Horton, Rudick, Hara-Cleaver, & Marrie, 2010; Ng, Low, & Thumboo, 2015; Sridharan,

Berdeprado, Vilar, Roberts, & Farrington, 2014) for the study. The survey (Appendix D) asked participants to indicate which of 16 diseases they had and provided explanations or examples for medical terminology that might cause confusion to participants (e.g., connective tissue disease, cerebrovascular, peptic ulcer disease, etc.).

Mediating Variables

Post-KT SM. Post-KT SM includes the range of behaviors patients perform in managing their own care, such as ways they follow prescribed post-transplant treatment regimens, promote their own health, prevent health deterioration, and preserve graft function (Berger, 2014; Gordon, Gallant, Sehgal, Conti, & Siminoff, 2009; Haspeslagh et al., 2013; Kasiske et al., 2010). To be more specific, KT SM includes IS medication management, adherence to post-transplant treatment regimen, healthy lifestyle maintenance including regular exercise, proper diet and weight management, allograft function self-monitoring, infection prophylaxis, skin cancer precautions, and decision-making about seeking care (Haspeslagh et al., 2013; Hedayati, Shahgholian, & Ghadami, 2017; Kasiske et al., 2010; Ndemera & Bhengu, 2017; Schäfer□Keller, Steiger, Bock, Denhaerynck, & De Geest, 2008).

The study measured SM behaviors using the new PI-developed 29-item KT-SM scale. Think-aloud interviews conducted by the investigator with six adult KT recipients (three females and three males) recruited from the KT program at Indiana University Health demonstrated face validity (Table E-1). Content validity was established with a CVI of 0.931 (Table F-1). The items are scored on a 5-point Likert-type scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). Scores were totaled for a total score and

for single domain scores. Higher scores indicated that the KT recipients engaged in the desired post-transplant SM behaviors.

Patient activation. Patient activation conceptually is defined as the level of a patient's active engagement in his or her own care and the knowledge, skill, and confidence the patient has about his or her ability to improve and maintain health, collaborate with healthcare providers, make decisions, and seek appropriate care (Hibbard et al., 2004; Shively et al., 2013; Smith, Curtis, Wardle, von Wagner, & Wolf, 2013).

The study measured patient activation with the 13-item PAM (Hibbard et al., 2005; see Figure A-2 for permission). The PAM is an interval level, Guttman-like scale with scores ranging from 0–100. Test scores were categorized into four levels, with Level 1 (*the lowest patient activation level*) and Level 4 (*the highest patient activation level*).

Self-efficacy. Self-efficacy is an individual's confidence in his or her own capability to successfully perform given tasks and achieve a preset goal (Bandura, 1997; Bodenheimer et al., 2002). Patients with high self-efficacy engage more in SM behaviors and have better physical function and quality of life (De Pasquale et al., 2014; Mersal & Aly, 2014; Weng et al., 2010).

The study measured participants' self-efficacy with the SEMCD 6-item scale (Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001). The investigator asked (see Table G-1) participants about their confidence levels of managing emotional distress, physical discomfort, illness condition, and low energy related to their chronic disease with questions such as: "How confident are you that you can keep from getting discouraged when nothing you do seems to make any difference?" Responses ranged from 1 (*Not at*

all confident) to 10 (*Totally confident*). Possible total scores range from 6 to 60. A lower score indicates that the patient has less efficacy in self-managing post-transplant care.

Outcome Variable

The conceptual definition of HRQoL is an individual's subjective experiences of satisfaction with his or her physical, emotional, social functioning, and well-being (Maglakelidze, Pantsulaia, Tchokhonelidze, Managadze, & Chkhotua, 2011; Molnar-Varga et al., 2011; Shumaker, Ellis, & Naughton, 1997). Data was measured with the 25-item KTQ-25 (Laupacis et al., 1993; Appendix H). Questions on the KTQ-25 are measured with a 7-point Likert-type scale and incorporate five disease-specific dimensions including physical symptoms, fatigue, appearance, uncertainty/fear, and emotion (Appendix H). Scores are summed for a total score and for five single domain scores. A higher score indicates good quality of life (Laupacis et al., 1993; Neipp et al., 2006).

Summary

Despite the tremendous improvement in first-year graft survival and reduction in episodes of acute kidney rejection, the 5- and 10-year graft survival rates after KT have seen little improvement over the past decades. Moreover, the top three leading causes of death among the KT population are CV disease, infection, and cancer; as a result, many transplant recipients die prematurely with a functioning allograft. Whether effective post-KT SM can improve long-term post-transplant outcomes including HRQoL still is unclear. Likewise, little is known about how KT recipients manage their post-transplant condition by maintaining a healthy lifestyle, engaging in cancer precautions and infection prophylaxis, self-monitoring graft function, and taking medications as prescribed. An

instrument capable of identifying and measuring post-transplant SM behavior may help healthcare providers and researchers provide tailored interventions based on individual need. Existing instruments to measure these behaviors have limitations. Therefore, the investigator in this study developed a new KT-SM scale and tested its psychometric properties. This study also examined associations among self-efficacy, patient activation, and post-KT SM behavior as well as whether SM is associated with post-transplant HRQoL.

Chapter Two presents a literature review of the current state of science regarding risk factors and potential variables of post-KT SM behavior and long-term outcomes. The chapter discusses research findings regarding SM behaviors and reviews existing post-KT SM scales.

CHAPTER TWO

REVIEW OF THE LITERATURE

Chapter Two provides a literature review of the current state of science regarding contributing risk factors and potential mediating/moderating variables pertaining to post-KT SM behavior and long-term outcomes. This chapter consists of four sections that cover risk factors/antecedents that contribute to non-adherence to post-transplant SM behavior, self-efficacy and patient activation and their relationships to post-transplant SM behaviors, post-KT HRQoL and its relationship to SM, and a review of existing post-KT SM scales.

Antecedents/Risk Factors

Demographic Factors

The risk factors contributing to poor post-KT outcomes and non-adherence behavior such as graft loss, IS medication non-adherence, and low HRQoL are well established and include older age, low income, unemployment, non-White race, male gender, single status, and low education level (Gordon, Ladner, Caicedo, & Franklin, 2010; Malek, Keys, Kumar, Milford, & Tullius, 2011; Scheel et al., 2018). Likewise, these demographic factors are accepted widely as risk factors in chronic condition SM behaviors, but little is known about how they affect specific post-transplant SM behaviors. The following sections examine the relationships among demographic factors, post-transplant SM, and HRQoL.

Age. As wait times for KTs increase, the number of candidates on wait lists who are aged 50 years and older has increased over the past 10 years (Hart et al., 2017; Matas et al., 2015). Moreover, the number of elderly KT recipients is growing rapidly because

of the aging of the U.S. population (Englum et al., 2015; Gill et al., 2013; Gill et al., 2011; Hart et al., 2017; Knoll, 2013; McAdams-DeMarco, James, Salter, Walston, & Segev, 2014). Since 2005, approximately 2,200 to 3,100 recipients over age 65 have received KT surgeries each year, and the number is expected to increase (Matas et al., 2015). There also is increasing concern regarding elderly recipients' post-KT outcomes. Elderly KT recipients have more comorbidities prior to transplant (Legendre et al., 2014) and frequently undergo transplant surgeries with allografts from older deceased donors because of new Organ Procurement and Transplant Network (OPTN) deceased-donor kidney-allocation policies (Gill et al., 2013; Pinter et al., 2017). According to these policies, each kidney candidate is assigned an Expected Post-Transplant Survival (EPTS) score and the donor kidney quality is measured by the Kidney Donor Profile Index (KDPI). The EPTS score is calculated based on candidate's age, time on dialysis, and history of previous transplant. Kidney candidates with the top 20% of EPTS scores are offered the best-quality donor kidneys first. Candidates with older age are less likely to be offered a high-quality donor kidney (OPTN, 2014).

Older age in kidney candidates also presents a potential barrier to IS medication adherence and SM of chronic conditions. Kidney recipients aged 65 years or older tend to be less adherent to treatment regimens, perhaps because of vision or memory problems, complexity of the therapeutic regimen, limited physical function, or difficulty in swallowing (Chisholm, Melroy, Johnson, Malloy, & Spivey, 2008; Griva, Davenport, Harrison, & Newman, 2012; Russell et al., 2010; Shetty, Wertheim, & Butt, 2017). Moreover, researchers estimate that more than 65% of people aged 65 or older have more than two comorbid conditions, and an increased number of comorbidities and poor

physical function have been reported as barriers to SM in this population (Bayliss, Ellis, & Steiner, 2007).

Race. Being African American is positively associated with poor transplant outcomes and non-adherence to medical treatment (Butler, Peveler et al., 2004; Contreras et al., 2012; Gonzalez-Suarez & Contreras, 2017; Gordon et al., 2010; Keith & Patrie, 2011; Patzer & Pastan, 2013). Other studies indicate risk factors contributing to shorter graft survival among African Americans include strong cell-mediated immune response, different pharmacokinetic mechanisms than Whites, medication non-adherence, high prevalence of diabetes mellitus and hypertension, and unequal access to KT because of late referral to transplant physicians (Gonzalez-Suarez & Contreras, 2017; Gordon et al., 2010; Legendre et al., 2014; Malek et al., 2011; McGee et al., 2011). In a cohort study conducted by the Department of Veterans Affairs that enrolled 79,361 KT recipients, African American KT recipients had a 30% higher risk of allograft failure compared to non-African American KT recipients (relative risk 1.31; 95% CI 1.26 to 1.36; Chakkera et al., 2005). Results of another retrospective study confirmed that African Americans had the highest graft failure rate among all ethnic groups, experienced more CV events, and had higher prevalence of hypertension and diabetes mellitus (Palanisamy et al., 2015; Taber, Egede, & Baliga, 2017).

Gender. Women have a lower probability of being placed on the KT list than men and thus have limited access to transplants (Lipford et al., 2018; Monson et al., 2015). A multi-center study of 4,118 KT recipients indicated that women had a 28% lower transplant rate than men (Jindal, Ryan, Sajjad, Murthy, & Baines, 2005). Despite gender disparities in access to KT, women have better survival rates as compared to men

(Vahed, Samadi, Mostafidi, Ardalan, & Omidi, 2016). This fact may be because women possess better health-related knowledge, utilize healthcare more effectively, are more compliant with IS medication regimens, actively seek care, and demonstrate more concern about protecting kidney function (Jindal et al., 2005; Puoti et al., 2016). However, the results are inconsistent in the literature. Johnson, Wicks, Milstead, Hartwig, and Hathaway (1998) conducted a survey to examine if gender had any effect on post-KT HRQoL, an important indicator of post-transplant patients' recovery. Each participant completed an HRQoL questionnaire at baseline, 6-, and 12-months' post-transplant. Although HRQoL improved after transplant in both genders, the HRQoL scores were consistently lower in women ($p \leq .005$).

Whether gender affects post-transplant SM behavior has not yet been well examined. Studies regarding patient SM behaviors in diabetes and heart failure have shown that women experience more psychosocial distress than men, report more depressive symptoms, lack social support, and experience poor physical function and comorbidities. Each of these factors contribute to not engaging in SM activities (Boerner, Eccleston, Chambers, & Keogh, 2017; Chesla, Kwan, Chun, & Stryker, 2014; Heo, Moser, Lennie, Riegle, & Chung, 2008; McCollum, Hansen, Lu, & Sullivan, 2005).

Marital status and education level. People who are unmarried, live alone, or have little social support have been shown to have poor health outcomes and to be non-adherent to medical regimens (Gerull et al., 2017; Griva et al., 2012; Hucker et al., 2017; Taber et al., 2016). Studies have shown that education level is positively associated with health literacy, medication adherence behaviors, and graft survival (Demian, Shapiro, & Thornton, 2016; Hod & Goldfarb-Rumyantzev, 2014; Morony et al., 2018;

Taber et al., 2016). In addition, patients with fewer than 12 years of education were less likely to be placed on the transplant wait list compared to college graduates. Possible explanations may be that patients with more education demonstrate better health literacy, possess the ability to seek health information, have access to healthcare resources, and communicate more effectively with healthcare providers. Patients with higher education also have been found to have lower mortality and less graft loss (Hod & Goldfarb-Rumyantzev, 2014). However, the results are mixed; the KT literature also reported a tendency of KT recipients with higher education to be non-adherent (Dobbels et al., 2010; Gelb, Shapiro & Thornton, 2010; Griva et al., 2012; Prendergast & Gaston, 2010).

Employment. Unemployed KT recipients have much higher rates of post-KT graft loss, mortality rates, and low HRQoL compared to those who are employed (Begaj, Khosla, Ray, & Sharif, 2013; Danuser, Simcox, Studer, Koller, & Wild, 2017; Nour, Heck, & Ross, 2014; Prihodova et al., 2015; Tzvetanov et al., 2014). The majority of KT recipients are between the ages of 18 and 64 years during which period adults are commonly employed; therefore, it is expected that KT recipients will return to productive roles after successful transplants (Tzvetanov et al., 2014). Full-time employment is a source of income and health insurance, as well as a significant indicator of an individual's health recovery (Danuser et al., 2017; Ferrario, Verga, Piolatto, & Pira, 2014; Nour et al., 2014; Tzvetanov et al., 2014). However, the post-KT employment rate is lower than that of the general population. The employment rate post-transplant is between 28%–58% (Danuser et al., 2017). Nour et al. (2014) surveyed 60 KT recipients in Canada (average age 49.4 years) and reported that pre-transplant employment rates

decreased (p = .00) from 68.3% prior to the transplant to 38.3% post-transplant, while the retirement rate increased 10% post-transplant. Nour et al. (2014) and Tzvetanov et al. (2014) also found that unemployed KT recipients were more likely to be elderly, live alone, have a low education level, live on a limited income, and perceive low emotional and physical health status (p < .01). Other researchers have found that people who were non-diabetic, employed before transplant, and aged 25–54 years had higher rates of returning to full-time employment post-transplant (Danuser et al., 2017; Helanterä, Haapio, Koskinen, Grönhagen-Riska, & Finne, 2012)

Clinical Variables

Comorbidities. Achieving optimal clinical outcomes in patients with chronic conditions mainly depends on the patient's SM. However, SM behaviors can be complex for individuals with multiple comorbidities (Bayliss et al., 2007; Schulman-Green et al., 2012). Kerr and colleagues (2007) conducted a survey with 1,901 diabetes patients and found that an increased number of comorbidities is negatively correlated to SM ability and disease prioritization (p < .001). The presence of comorbidities is one of the predictors of post-KT outcomes, and the increased number of comorbid conditions is positively associated with higher patient mortality and graft loss (Cossart, Staatz, Campbell, Isbel, & Cottrell, in press; Vranian et al., 2018; Wu et al., 2005).

Jassal and colleagues (2005) analyzed 6,324 Canadian KT recipients and found that 21% had at least one comorbid condition. Machnicki et al. (2011) examined United States Renal Data System data for 24,963 deceased KT recipients between 1995–2002 and found that 25% of KT recipients had more than three comorbidities per the CCI, and 20% had more than six comorbidities per the Elixhauser Comorbidity Index. In the

Machnicki et al. analyses, the most reported comorbidities were hypertension (74.73%) and diabetes (30.47%). Furthermore, investigators (Chakkera et al., 2005) estimate that 15%–30% KT recipients will develop new onset diabetes after transplantation (NODAT) within one-year post-transplant. Those KT recipients with NODAT also have been found to have up to 60% increased incidence of graft loss and 90% increased mortality risk (Chakkera et al., 2005). In addition, CV disease is the leading cause of death in KT recipients, and diabetes, hypertension, dyslipidemia, obesity, and use of immunosuppressant corticosteroids and tacrolimus are well established CV risk factors (Carpenter et al., 2012; Laging et al., 2016; Vanrenterghem et al., 2011; Young, Kupzyk, & Barnason, 2017).

Duration on pre-transplant dialysis. Evidence suggests that longer duration on pre-transplant dialysis links to increased risk factors for CV events and cancer, which are the major causes of death among KT recipients (Haller, Kainz, Baer, & Oberbauer, 2017; Helanterä et al., 2014; Remport et al., 2011; Wong et al., 2013). Chronic dialysis patients have an increased cancer risk compared to age-matched general population, and KT recipients are at even higher cancer risk because of side effects from IS medication. Studies suggest that chronic pre-transplant dialysis is an independent risk factor contributing to increased patient mortality and graft loss rates; KT recipients with fewer than one year or one to three years of pre-transplant dialysis demonstrate better transplant outcomes than KT recipients with more than three years of dialysis (Helanterä et al., 2014; Remport et al., 2011; Wong et al., 2013).

Type of KT. Those KT recipients who receive a kidney from a living donor have approximately 50% less graft loss after one year and 80% less graft loss after two years

than patients who receive a kidney from a deceased donor (Chisholm-Burns, Erickson, Spivey, & Kaplan, 2012; Denhaerynck et al., 2007; Gremigni et al., 2007; Hansen, Seifeldin, & Noe, 2007; Hart et al., 2017; Prendergast & Gaston, 2010). In addition, kidneys may come from a related or unrelated living donor; both types of living KT share similar long-term outcomes (Davis & Delmonico, 2005).

Post-Transplant SM, Patient Activation Level, and Self-Efficacy

Post-Transplant SM

In chronic conditions, SM is defined as the actions taken to manage the impact of the chronic condition in all aspects of daily life; this process involves attitudes, behaviors, and skill sets (Lawn & Battersby, 2009). In KT, SM is the range of behaviors patients perform in managing their own care, including ways they follow prescribed post-transplant treatment regimens, promote their own health, prevent health deterioration, and preserve graft function (Berger, 2014; Gordon et al., 2009; Haspeslagh et al., 2013; Hedayati et al., 2017; Kasiske et al., 2009). To be more specific, KT SM includes IS medication management, adherence to post-transplant treatment regimen and diet recommendations, self-monitoring of allograft function, infection prophylaxis, decision-making about seeking care, and physical function maintenance, lifestyle modification (e.g., weight management), and skin cancer precautions (Haspeslagh et al., 2013; Hedayati et al., 2017; Kasiske et al., 2009; Schäfer-Keller et al., 2008).

SM and medication adherence. The definition of medication adherence includes no missed medication episodes, timely prescription refills, seeking help from a health professional to adjust medication or dose if any acute side effects present, and taking medication as prescribed including time, frequency, and correct dosage (Butler, Roderick

et al., 2004; Nevins, Nickerson, & Dew, 2017). Unfortunately, KT recipients have the highest medication non-adherence rate among all types of organ transplant patients at 35.6% per year (Russell et al., 2010). Poor post-KT outcomes may be attributed to poor IS medication adherence (Nevins et al., 2017). Adherence to IS medication regimens is the major predictor of the long-term outcome of the transplanted kidney, with consequences of poor IS medication adherence including graft failure, return to dialysis, second transplant, or death (Low, Williams, Manias, & Crawford, 2014; Reese et al., 2017; Russell et al., 2010).

Kidney shortage is a major problem facing patients with end-stage renal disease (ESRD) or kidney failure. The demand for KT increases each year. As of January 30, 2018, a total of 95,296 candidates were on the wait list, according to the UNOS (n.d.). Maximizing the survival of transplanted kidneys by promoting KT recipients' medication adherence is crucial considering the demand for kidneys, the negative impact of IS medication non-adherence on transplant outcomes, and the economic burden of non-adherence (Marsicano et al., 2015; Reese et al., 2017).

Factors associated with poor adherence to IS regimens include forgetfulness and complexity of post-transplant regimens (Dobbels et al., 2010; Gheith, El-Saadany, Abuo Donia, & Salem, 2008; Nevins et al., 2017; Russell et al., 2007; Simons & Blount, 2007). Greenstein and Siegal (1998) reported that 47% of non-adherence was the result of accidental forgetting. This type of non-adherence may be improved by assisting KT recipients to form habits, create organization, and simplify medication dosing (Cossart et al., in press). Kuyper et al. (2013) conducted a randomized multi-center controlled trial to assess the impact of once-daily IS regimens (QD) compared to twice-daily regimens

(BID) on KT recipients' medication adherence ($N = 219$). Each participant had been taking a twice-daily regimen for 3 months, and 145 participants were assigned randomly to the QD group. The QD group showed higher adherence rates than the BID group during the 6 months after the intervention ($p = .0009$).

After-transplant IS medication non-adherence is a complex behavioral issue. Transplant recipients who perceived the benefits of the transplant and associated treatment in their lives were motivated to be adherent to their treatment regimens (Dobbels et al., 2017; Mellon et al., 2017). However, motivation is not a stable and strong predictor for KT recipients following treatment regimen. The medication-adherent behavior of KT recipients declines over time post-transplant. For example, Massey and colleagues (2015) showed that KT recipients' medication adherence decreased to 69% at 18 months post-transplant. The perceived necessity of medication and the perceived impact of the transplant on HRQoL also decreased. Understanding KT recipients' exceptions of allograft outcomes, perceived barriers to following a treatment regimen, and motivations to maintain medication adherence behaviors and integrating these with SM goals may help promote treatment adherence in this population (Massey et al., 2015; Nevins et al., 2017).

Researchers have suggested that interventions to promote medication adherence should combine education with behavioral and social support (Denhaerynck et al., 2005; Nevins et al., 2017; Scheel et al., 2018). Chisholm-Burns et al. (2013) conducted a pharmacist-led intervention study to evaluate whether a one-year behavioral intervention program impacted kidney recipients' medication adherence behaviors, healthcare utilization, and cost. Patients in the intervention group ($n = 76$) were highly adherent to

medication compared to the control group ($p < .0001$) and had lower hospitalization rates of 23.9% during the 12 months of the study compared to the control group's 57.3%. Fewer hospitalizations resulting in cost savings also were noted.

SM and clinical outcomes. The results of numerous studies have shown that efficacious SM helps patients with chronic illness to reduce distress and leads to less re-hospitalization, fewer emergency room visits, and reduced healthcare costs by preventing or alleviating disease progress. Furthermore, those individuals who effectively self-manage their illness ultimately have better quality of life (Lorig & Holman, 2003; Novak, Costantini, Schneider, & Beanlands, 2013; Redman, 2007, 2009; Zimbudzi, Lo, Ranasinha, Kerr, Usherwood et al., 2017). Among the Type 2 diabetes population, Norris, Lau, Smith, Schmid, and Engelgau (2002) systematically reviewed 31 randomized controlled trials to examine the effects of a diabetes SM education intervention on type 2 diabetes glycemic control at baseline and at follow-up intervals. The results showed that the interventions decreased HgbA1C by 0.76% (95% CI, 0.34–1.18) more than the control group. SM skills, behavior, and habits may take time to learn and form (Steinsbekk, Rygg, Lisulo, Rise, & Fretheim, 2012). Steinsbekk et al. (2012) reviewed 21 randomized controlled trials and found that clinical outcomes including HgbA1c ($p = .006$), lifestyle, SM skills ($p = .001$), and diabetes knowledge were significantly improved at 6 months ($p = .00001$).

Hypertension, diabetes, and chronic kidney disease are well established as risk factors for CV events. McManus et al. (2014) conducted a randomized controlled trial that included 552 adult hypertensive patients with coronary heart disease, diabetes, or chronic kidney disease to examine the effect of SM on blood pressure control. At 12

months, participants in the intervention group had reduced their mean systolic blood pressure by 9.2mmHg (95% CI, 5.7–12.7) and diastolic blood pressure by 3.4mmHg (95% CI, 1.8–5.0) compared to the usual care group.

SM and physical function. Transplant recipients' physical function is tied to post-transplant mortality and outcomes (Lorenz et al., 2017). Death and CV events with functioning graft are linked strongly to low physical activity (Afsar et al., 2018). Regular exercise has been found to improve physical function and quality of life in the transplant population (Mathur et al., 2014; O'Connor et al., 2017). Cramm and Nieboer (2012) conducted a study in the Netherlands to examine correlations between SM abilities, physical function, and depressive symptoms in patients with CV disease, chronic obstructive pulmonary disease, and diabetes (N = 2,899). They found that SM abilities can be used to predict physical function and depressive symptoms in all groups ($p <$ .0001), and as SM abilities increased, the decline of physical function slowed and there were also fewer depressive symptoms.

SM and lifestyle modification. Long-term use of IS medications is associated with high risk of developing NODAT, CV disease, dyslipidemia, obesity, and hypertension, all of which are linked to graft loss and mortality (Ahmadi et al., 2014; Cooper et al., 2017; Glicklich, Lamba, & Pawar, 2017; Sarno et al., 2012). Researchers estimate that more than 50% of kidney recipients will have weight gain at 12 months post-transplant (Cashion et al., 2014; Chan et al., 2014; Kugler et al., 2015). Adhering to lifestyle recommendations including healthy diet, exercise, and weight loss has been found to reduce CV risk (Chow et al., 2014; Klaassen et al., 2017; Lidin, Ekblom-Bak, Rydell Karlsson, & Hellénius, 2017). In chronic disease populations, de Alba Garcia and

colleagues (2007) interviewed 62 Mexican diabetes patients in their investigation of lifestyle modification and SM behavior attributed to good HbA1C control (< 7.0%). The study results demonstrated that patients with well controlled HbA1C exercised regularly, ate a healthy diet, and knew their target blood glucose level. Pettman et al. (2008) conducted a lifestyle intervention study in Australia with 153 overweight/obese (mean BMI was 36.6 ± 0.7) adults with metabolic syndrome. Investigators randomly assigned participants to control group and intervention group. Both groups were provided education booklets about healthy eating and physical activity, but the intervention group additionally was provided with exercise sections and lifestyle SM information classes 2 hours per week for 4 months. Results indicated that reduction in body fat mass, blood pressure (DBP $r = -0.31$, $p < 0.001$; SBP $r = -0.28$, $p = 0.01$), cholesterol ($r = -0.35$, $p < 0.001$), and glucose ($r = -0.35$, $p < 0.001$) were positively correlated with attendance at exercise and information sessions.

SM and skin cancer screening. Cancer is one of the leading causes of death in the KT population (Kato et al., 2016; Wong, Chapman, & Craig, 2014). Skin cancer mortality in U.S. KT population was reported at 35.25 per 100,000 person-year (Garrett, Lowenstein, Singer, He, & Arron, 2016). Transplant recipients are at 10- to 250-fold greater risk of developing nonmelanoma skin cancer because of the combined effects of long-term use of IS medication and ultraviolet radiation exposure or certain types of viral infection. In addition, the risk of developing nonmelanoma skin cancer increases with time under IS medication treatment (Bannon et al., 2014; Burke et al., 2015; Engels et al., 2011; Kang, Sampaio, Huang, & Bunnapradist, 2017; Wheless, Jacks, Potter, Leach, & Cook, 2014). Monthly skin and lip self-examinations, annual clinical skin examinations,

and sun protective precautions are recommended for transplant recipients to detect and prevent skin cancers (Acuna et al., 2017; Feuerstein & Geller, 2008; Kasiske et al., 2010).

Interventions related to skin cancer prevention have been found to effectively promote participants' engaging in self-skin examination and sun protection behaviors (Tsai, Frank, & Bordeaux, 2017). A randomized controlled trial assessed effectiveness of skin cancer education on sun protective behavior, self-skin examination, and knowledge regarding skin cancer among African Americans. Tsai et al. (2017) reported a statistically significant score difference between pre-intervention and post-intervention for sun protective behavior ($p < .02$), confidence in conducting self-skin examination ($p < .001$), and knowledge regarding skin cancer risk ($p = .001$).

Oliveria et al. (2004) conducted a case control study of the effect of a nurse-led education intervention on patients' adherence to self-skin examination ($n = 100$). At 4-month follow-up, 61.2% of the patients in the intervention group reported performing self-skin examination more than three times during the past 4 months ($p = 0.039$) compared to 37% of the control group ($p = 0.001$). Males aged 50 years or greater have a higher incidence rate and death rate of skin cancer than females. Janda and colleagues (2014) conducted a randomized clinical trial with 870 men aged 50 years or older. Participants were randomly assigned into a brochure-only group and a video-based intervention group. Both groups reported receiving a physician-conducted skin examination in the previous 6 months (56.4% for intervention group and 52.8% in control group, $p = .28$), but 35.3% of the intervention group performed a whole-body self-skin examination compared to 27.2% of the control group ($p = .01$). Robinson et al. (2014) aimed to enhance sun protection behaviors in the KT population. Robinson and

colleagues found that knowledge and perception regarding the risk of developing skin cancer, attitude toward sun protection, and willingness to engage in behavior change were significantly higher in the intervention group ($p < 0.01$); engaging in sun protection behaviors was significantly higher in the intervention group ($p < 0.013$).

SM summary. Post-KT SM is a complex and multi-dimensional task; kidney recipients are expected to self-manage their own care actively. However, it must be kept in mind that post-transplant SM is a lifelong, day-to-day task for kidney recipients, and SM skills and behaviors do not develop spontaneously and persist without support from healthcare professionals (Dwarswaard, Bakker, Staa, & Boeije, 2015; Hedayati et al., 2017). Novak and colleagues (2013) reported that education is a crucial part of SM support. Furthermore, the patient's readiness to learn about his or her care needs should be identified before intervening.

In addition to focusing on self-managing general clinical conditions, this literature review addressed SM interventions that can enhance and promote a healthy lifestyle and reduce cancer and CV disease risk. The relationships among patient activation, SM behaviors, HRQoL, and demographic variables/antecedents also were depicted in this literature review. Previous studies of SM in other chronic disease populations have indicated that perceived self-efficacy has direct effects on SM behaviors, and there is a positive correlation between patient activation and SM behaviors. Thus, this study examined the relationships among self-efficacy, patient activation, and disease-specific SM behaviors and their association with post-transplant SM and HRQOL in the KT population.

Patient Activation

The individual plays an active role in managing his or her own care and has the knowledge, skill, and confidence to improve and maintain health, collaborate with healthcare providers, and seek appropriate care and information (Bilello et al., 2018; Hibbard et al., 2004; Shively et al., 2013; Smith et al., 2013). Highly activated patients are more likely to perform health-related behaviors including self-managing behaviors, adapting to healthy lifestyle, and seeking health information (Bilello et al., 2018; Hibbard, 2017; Nijman et al., 2014; Ryvicker et al., 2013; Shively et al., 2013). Individuals with a high patient activation level have been shown to be more successful in controlling HgbA1C by self-monitoring blood glucose, following diet and treatment recommendations, and modifying their lifestyles (Sacks, Greene, Hibbard, Overton, & Parrotta, 2017; Salgado et al., 2017). Patient activation levels also are negatively correlated with 30-day post-discharge readmission and emergency room visits (Greene & Hibbard, 2012; Hibbard et al., 2004; Mitchell et al., 2014).

Magnezi et al. (2014) studied the relationships among patient activation levels, quality of life, and depressive symptoms for 278 subjects recruited from two primary care clinics in Israel. They found that PAM scores were negatively correlated with scores on the Patient Health Questionnaire-9 ($r = -0.35$, $p < .0001$) and positively correlated with scores on the 12-Item Short Form Health Survey (SF-12; $r = 0.39$, $p < .0001$). Evangelista et al. (2015) investigated the effect of an intervention program on patient activation, self-care, and quality of life among heart failure patients. The Evangelista et al. study revealed positive associations among patient activation ($r = 0.658$, $p < .0001$), self-care maintenance ($r = 0.335$, $p = 0.033$), and overall quality of life ($r = 0.329$,

p = 0.35). Demographic characteristics associated with PAM scores were reported in other studies; men, individuals with 12 or more years of education, higher income earners, and younger people scored higher on the PAM (Hendriks & Rademakers, 2014; Nijman et al., 2014).

Self-Efficacy

Self-efficacy is one's belief or confidence in being able to successfully master a given task (in this case, SM behavior) and reach the desired goal (Bandura, 1997; Denhaerynck et al., 2007). In chronic disease SM studies, interventions intended to improve self-efficacy have shown positive effects on individuals' health promotion practices and on patient outcomes (Andela et al., 2017; Chirico et al., 2017; Farrell, Wicks, & Martin, 2004; Lorig & Holman, 2003). Moreover, perceived self-efficacy has been shown to be positively associated with health behavior change and maintenance including medication adherence, following exercise or diet recommendations, and stress management (Chirico et al., 2017; Kauric-Klein, Peters, & Yarandi, 2017; Tokdemir & Kav, 2017; Weng et al., 2010). Sarkar et al. (2006) examined the relationships between diabetes SM behavior and self-efficacy and found that self-efficacy for diabetes SM was positively associated with four of five SM domains ($p < .01$), including following diet recommendation, exercising regularly, self-monitoring blood glucose, and foot care. Jones and Riazi (2011) systematically reviewed 22 articles on post-stroke self-efficacy and SM and concluded that self-efficacy is positively associated with various post-stroke outcomes including quality of life, perceived health status, less depressive syndrome, and higher physical functioning.

In KT studies, the correlations between self-efficacy and medication adherence behavior have been well examined (Weng, Yang, Huang, Chiang, & Tsai, 2017). De Pasquale et al. (2014) conducted a study with 120 Italian KT recipients and found positive correlations between self-efficacy, disease management, and quality of life. De Pasquale et al. also found that high self-efficacy was correlated with mental health; for example, as self-efficacy increased, patients' perceived mental health improved. Similarly, KT recipients with higher self-efficacy also scored higher on problem-solving, patient–provider partnership, medication adherence, and self-care/self-managing behavior (Weng et al., 2010; Weng et al., 2017).

In summary, self-efficacy has been used to predict a broad range of both physical and psychological health behaviors and health outcomes. It is positively correlated with treatment adherence, quality of life, SM behaviors, physical function, and mental health.

HRQoL

Factors that Influence HRQoL

Tharavanij and colleagues (2008) reported that KT recipients have higher HRQoL compared to dialysis patients and ESRD patients. Nevertheless, KT may not fully restore KT recipients' level of HRQoL to that of the general population. In addition, decreased HRQoL can result in patients' treatment non-adherence behavior (Tharavanij et al., 2008). Researchers report that patients' perceived HRQoL reflects their current health status (Joekes, Van Elderen, & Schreurs, 2007). As a result, HRQoL has been recognized as an imperative post-transplant outcome (Fujisawa et al., 2000; Kugler et al., 2013; Prihodova et al., 2014). Clinical and psychological risk factors that negatively impact post-transplant outcomes also have negative effects on HRQoL among the KT

population, including depression, age, unemployment, immunosuppressant side effects, limited physical function, diabetes, CV disease, serum level of creatinine, and glomerular filtration rate (Fujisawa et al., 2000; Griva et al., 2013; Molnar-Varga et al., 2011; Ortiz et al., 2014; Prihodova et al., 2014).

HRQoL and Clinical Outcomes

Can a patient's perceived HRQoL be used to predict KT long-term mortality and graft loss risk factors? In a 12-year longitudinal study conducted in the United Kingdom (Griva et al., 2013), 347 KT recipients were asked to complete the Medical Outcomes Study Short Form-36 (SF-36) at baseline. Eighty-six (24.8%) KT recipients died during the 12-year follow-up period; of these, 64 died with a functioning graft. In addition, 38 KT recipients had returned to dialysis. Lower physical HRQoL increased risk of mortality and graft failure significantly during the study period. The physical component score of the SF-36 was associated with long-term mortality and graft failure after adjusting for risk factors such as CV disease; long-term mortality and graft survival could also be predicted by HRQoL.

Another longitudinal study conducted in the Slovak Republic had similar results (Prihodova et al., 2014). A total of 151 KT recipients were asked to complete the ESRD check list, a socioeconomic and medical data questionnaire, and SF-36 at baseline. The results showed that KT recipients who perceived less severe medication side effects and demonstrated high self-efficacy for emotional coping were associated with higher HRQoL at baseline. Moreover, those who reported better graft function, high physical component and mental health component scores on the SF-36, and older age at baseline also reported better 10-year graft survival rate and lower patient mortality rates.

Prihodova et al. (2014) suggested that close monitoring of early HRQoL along with graft function at baseline could lead to improved odds of 10-year graft and patient survival rates.

HRQoL and SM

Better disease SM and lifestyle modifications have been shown to result in improved HRQoL (Kidd et al., 2017; Tharavanij et al., 2008). Gaston-Johansson et al. (2013) reported that a SM intervention effectively improved quality of life in patients with stage 2, 3, and 4 breast cancer ($N = 73$) who were undergoing chemotherapy. Gaston-Johansson et al. provided participants in the intervention group with education materials and taught relaxation and coping skills two weeks before the patients were admitted to the hospital, during chemotherapy treatment, and three months after discharge. All survey data from the Quality of Life Index-Cancer Version (correlation coefficient, 0.95) were collected at baseline and at one-year follow-up. There were statistically significant improvements in the intervention group in overall quality of life ($p < 0.01$), health and functioning ($p < 0.05$), and psychological/spiritual well-being ($p < 0.01$). E Vries and colleagues (2007) conducted a randomized controlled trial to determine if a general practitioner-led SM (SM) program resulted in improved Asthma Quality of Life (correlation coefficient, 0.95), limited activity days, and respiratory functions in asthma patients ($N = 214$). Asthma control, limited activity days, overall asthma quality of life ($p = 0.055$) and emotion domain ($p = 0.055$) were significantly improved in the SM group compared to the usual care group. McGillion et al. (2014) conducted a meta-analysis with nine trials included ($N = 1,282$) examining an SM intervention effect on stable angina symptoms, HRQoL, and psychological

well-being. Patients' HRQoL was measured with the Seattle Angina Questionnaire (SAQ), which consisted of four subscales: angina frequency, physical limitation, disease perception, and treatment satisfaction. The analytic results suggest that angina frequency (standard mean difference: 0.30 (95% CI 0.14, 0.47, $p = 0.0003$) and SAQ physical limitation (95% CI 0.20, 0.55, $p < 0.0001$) were significantly improved by the SM intervention.

However, the results reported in the literature are inconsistent. Walters et al. (2013) conducted a randomized controlled trial to evaluate the effectiveness of a telephone-delivered health-mentoring intervention for chronic obstructive pulmonary disease patients. The HRQoL of these patients was measured using the SF-36 and St. George's Respiratory Questionnaire, with data collected at baseline, 6 months, and 12 months. Findings showed no difference in the quality of life scores in both groups, although SM capacity (95% CI 0.03 to 0.29) and knowledge (95% CI 0.00 to 0.50) increased in the SM group. Weng et al. (2010) reported similar results; they found a positive correlation between self-efficacy and SM in KT recipients, but no direct effect on the physical component of the SF-36.

HRQoL Summary

In past studies, HRQoL has been recognized as an important post-transplant outcome measure because it is an indicator of treatment effectiveness in KT. Risk factors associated with graft loss and patient mortality have been found to be associated with HRQoL as well. Recently, researchers have examined whether early post-transplant HRQoL can be used as a predictor in predicting long-term KT outcome. In the adapted KT-SM framework, HRQoL was used as a post-KT outcome because one of the study

hypotheses was that improvement in patient activation level would enhance transplant recipients' SM behaviors and further improve HRQoL in KT recipients.

Existing Post-KT SM Scales

There are three existing KT SM-related instruments (Kosaka et al., 2013; Schmid-Mohler et al., 2014; Weng et al., 2010). Table I-1 (Appendix I) presents a review of the KT SM scales. The following list categorizes the limitations of the three different SM scales:

1. Weak theoretical foundation: In developing a questionnaire that has validity and clinical usefulness (utility), a clear conceptual framework (or theory) is essential (DeVellis, 2012). The content of a measuring tool may not reflect the phenomenon of study without theoretical grounding (Jordan et al., 2013). Experts suggest that clear construct definition is the first and foremost step in scale development, and theory is an aid to clarifying the construct to be measured in study (DeVellis, 2012; Netemeyer, Bearden, & Sharma, 2003). Of the three KT SM scales, only the one by Schmid-Mohler et al. (2014) was developed according to Lorig and Holman's (2003) conceptualization of SM tasks and demonstrated logical consistency. Weng et al. (2010) claimed to use Bandura's concept of self-efficacy, but the authors failed to conceptually define self-efficacy and post KT self-care. Kosaka and colleagues (2013) did not report what framework/theory they used to guide the study.
2. Lack of construct definition: Items of each subscale do not reflect the researchers' SM definitions. For instance, Weng et al. (2010) indicated

that medication-taking behavior, better dietary control, and health-promoting behavior are associated with better quality of life post-KT but did not include items about any of these subjects in their scale. Kosaka et al. (2013) did not conceptually define post-transplant SM in their article.

3. Item writing and wording clarity: A good item should be straightforward to read, contain short sentences, consider the reading level of the target population, and avoid double-barreled items (DeVellis, 2012; Netemeyer et al., 2003). Schmid-Mohler and colleagues (2014) did not provide a sample of their written items and based on their description of their paper, they were at the beginning phase of item development. Many items in the existing scales were lengthy and can be considered double- or triple-barreled questions, such as "When decrease of urine or edema occurs, I would spontaneously control the absorption of water and take lesser salt" (Weng et al., 2010) and "I perform gargling and hand washing" (Kosaka et al., 2013) or were too general to answer, such as "I keep my house clean" (Kosaka et al., 2013).
4. Reliability or validity issues: Schmid-Mohler and colleagues (2014) did not report reliability and construct validity data. Neither Kosaka et al. (2013) nor Weng et al. (2010) reported construct validity statistics.
5. Translation quality and cross-cultural adaption issues: Translation quality is a major concern. These three scales were developed and tested in Taiwan, Japan, and Switzerland. The investigator in this study is a native

Chinese speaker, a U.S.-trained doctoral candidate, and can read Chinese and Japanese; the investigator requested English and source language (Japanese and Mandarin Chinese) versions of the scales by Kosaka et al. (2013) and Weng et al. (2010). Upon review, the English translations of some items did not match the original-language versions. The investigator used the backward translation procedure suggested by Sousa and Rojjanasrirat (2011) to translate Weng's English version back to Chinese and compared two versions. There were many discrepancies in meaning and word choice. Cross-cultural adaptation is another concern. Some items such as, "I would avoid going to public spaces where there are too many people or the air quality is bad," or "I would not eat strong flavored food" could have been developed based on geographic reasons and food preferences in Eastern culture. However, similar items are difficult to apply to the U.S. population. Therefore, it became clear to the investigator that a new, comprehensive, and specific scale is necessary for the U.S. KT population.

Summary

The chapter presented research findings regarding SM behaviors and reviews existing post-KT SM scales. It discussed risk factors/antecedents that contribute to non-adherence, self-efficacy and patient activation, and post-KT HRQOl. The chapter concluded by presenting the three existing KT SM scales. Chapter Three presents the methodology used in this study including participant eligibility, the study design, recruitment strategies and the data analysis methods used.

CHAPTER THREE

METHODOLOGY

This chapter describes the methods used to conduct the present study including participant eligibility criteria, study design development, discussion of the sample size for psychometric testing of the new KT-SM scale, methods and procedures used for recruiting the sample from Facebook, strategies to prevent survey non-response, protection of human subjects, and online data collection. A description of the data analysis methods also is included. The final section presents the results of the cognitive review and content validity scores of the new KT-SM scale.

Eligibility Criteria

The inclusion criteria for this study required KT recipients to: 1) be more than 18 years of age, 2) have received a KT that is still functioning, 3) be willing to complete a study survey, and 4) have been treated and received follow-up care in the U.S. Exclusion criteria included transplantation of any organ other than the kidney.

Study Design

The study used a cross-sectional, descriptive, correlational design. Data were collected using a self-administered, online survey developed and delivered through REDCap® (Research Electronic Data Capture).

Sample

To conduct factor analysis for psychometric testing of the KT-SM scale, the investigator selected a rule of five subjects per item for sample size estimation. The KT-SM scale contains 29 items; therefore, a sample size of 153 adult KT recipients was

sufficient for this study (DeVellis, 2012; Fall, Gauchet, Izaute, Horne, & Chakroun, 2014; Williams, Onsman, & Brown, 2012).

Considering that KT recipients constitute a relatively small population, to obtain a large enough study sample for psychometric testing a social network-based recruitment strategy using Facebook® was utilized. This strategy included a Facebook study page, Facebook support groups, and paid Facebook advertising. Facebook is the most popular social networking site in the U.S. and is used by an estimated 68% of American adults (Pew Internet & American Life Project, 2015). Facebook has been found in recent years to be an effective recruiting tool in health-related research including clinical trials and intervention studies (Kayrouz, Dear, Karin, & Titov, 2016; Pedersen et al., 2015; Pedersen & Kurz, 2016; Weiner, Puniello, Siracusa, & Crowley, 2017). Advantages of using social media recruitment include timely data collection, low cost, efficient use of recruitment efforts, wider coverage of the study population, and broader geographic range (Dillman, Smyth, & Christian, 2014; McPeake, Bateson, & O'Neill, 2014; Sikkens, van San, Sieckelinck, Boeije, & de Winter, 2017).

Studies using online surveys and Facebook as a recruitment tool have demonstrated that surveys with 10%–20% unanswered items may be accepted and included in the final data analysis (Akard, Wray, & Gilmer, 2015; Pedersen et al., 2015). In this study, surveys with 10% or more unanswered items were excluded from data analysis to ensure data quality. Two hundred and thirty-two adult KT recipients were needed based on an estimate of 60% nonresponse plus drop-out rates. Initially, 183 surveys were obtained. Of these, 30 surveys were eliminated because of

misrepresentation issues—that is, survey takers may not have been kidney recipients but were pretending they were. This left 153 usable surveys for the data analyses.

Procedures

Facebook Recruitment Methods

Using Facebook as a recruitment tool along with online surveys is cost- and time-efficient and makes it possible to approach hard-to-reach populations including young people, low-income populations, and small-in-number populations of interest (Batterham, 2014; Kayrouz et al., 2016; Sikkens et al., 2017; Weiner et al., 2017). The investigator found the following strategies effective in recruiting research participants using Facebook (Alshaikh, Ramzan, Rawaf, & Majeed, 2014; Amon, Campbell, Hawke, & Steinbeck, 2014; Ramo, Rodriguez, Chavez, Sommer, & Prochaska, 2014) for this study: creating and paying to promote a Facebook study page, recruiting from Facebook support groups, and paying for standard Facebook Ads.

Promoting the Facebook study page. The PI designed a Facebook study page (Figure J-1) to use as a recruiting tool and to address questions or concerns from potential participants. The investigator paid Facebook to promote the page, which increases visibility with a targeted audience (Facebook Business, *About business page promotions*, n.d.). To increase effectiveness of the Facebook study page itself as a recruiting source, the content of the page included descriptions of the study information and posts intended to recruit participants. The posts also included the study purpose, time required to complete the online survey, contact information of the PI, and a link to the REDCap study information and screening page. The investigator posted recruiting posts and

pinned (i.e., locked in a specific location) them on the timeline of the Facebook study page, so people who visited the page would see them.

A study page may be seen by more people when Facebook's page-promoting function is used, and Facebook users invite others to *like* (i.e., to indicate that a person supports the group associated with the page or the topic being discussed) and *share* (i.e., to post the information to their personal) the page. The cost of promoting the study page was determined by the desired number of people who see and click on the page per day. The minimum and maximum daily budget ranged from $5 for 3–14 likes per day to $20 for 17–69 likes per day. The investigator managed the money spent on page promotion using the *daily budget* and *promotion duration* through the Ads Manager function on the Facebook site. The PI adjusted the budget and advertising duration based on the number of survey respondents obtained in the first and subsequent weeks. The second method the investigator employed to increase Facebook study page visibility to a wider audience was to invite participants who had completed the survey and their friends to share or like the study page on their Facebook news feed or to leave comments on the study page. When people share, like, or comment on the study page, their Facebook contacts also may see the activities on their own Facebook newsfeed. Using these two methods reached some additional people who were not in any KT support groups.

Recruiting from Facebook support groups. The investigator conducted a search of Facebook to identify KT support groups. Key words used to conduct the search included transplant, kidney transplant, transplant support group, and transplant survivors. The search identified and targeted six KT-related support groups, which have a total of more than 30,000 members. The PI contacted the administrators of each group, and

administrators from three of the groups agreed to help in the recruiting process (Appendix K).

- Kidney Transplant Survivors and Donors has a total of 642 members (https://www.facebook.com/groups/390173347706273/members/);
- Kidney Transplant and Weight Loss has a total of 551 members (https://www.facebook.com/groups/637119173042669/); and
- Kidney Transplants has 888 members (https://www.facebook.com/groups/26240800215/).

In total, these three groups have a total of more than 2,081 members. Each support group administrator agreed to post and pin an initial public recruitment message on their Facebook support group page, and to post a second recruitment message one week later. They posted a thank you message two weeks after the second recruitment message (Appendix L).

Using standard Facebook ads. The investigator also used paid advertising in this study because the three KT support groups discussed in the previous section only consisted of approximately 2,000 members. The PI expected the number of accessible, eligible participants from the support groups to be even fewer because people can join Facebook KT support groups even if they are not recipients, not all members in the three targeted transplant support groups are living in the U.S., and memberships in the support groups were likely to overlap.

Paid Facebook advertisements have been found to be a time- and cost-effective method for recruiting participants, and the cost ranges from $1.35 to $8.88 per person (Akard et al., 2015; Pedersen et al., 2015; Thornton, Harris, Baker, Johnson, &

Kay Lambkin, 2016). Facebook advertisements can be targeted (this study's targets enclosed in parentheses) to age (aged 18 years and above), geographic location (U.S.), language (English), and Facebook users' interests within their profile (KT). Chan (2011) examined the impact of Facebook advertising on a university library's Facebook page. The Facebook ads in the Chan study were targeted specifically and displayed only to current students who had not yet liked the university library's Facebook page. After two months of Facebook ads, more than 50% of the new connections to the library's Facebook page were added through Facebook advertising.

There are two main types of Facebook advertising: impression-based and click-based (Facebook Business, *Impressions*, n.d.; Facebook Business, *Updating how cost per click is measured on Facebook*, n.d.). Impression ads display to a user viewing a Facebook page regardless if the user clicks on the ad or not. The cost of impression-based ads is determined by cost-per-thousand impression; for instance, the PI would pay $5 per day to have 1,000 people see the ad (impression). Click-based advertising is the cost-per-click; advertisers pay only when a viewer clicks their ads. To use Facebook standard ads more cost-efficiently, the investigator chose the cost-per-click method for the Facebook ad campaign in this study. The PI set the daily spending limit to $10 for the first week, with an overall limit set to $200.

Recruitment Messages

The Facebook recruitment strategy included the following messages: (1) a public recruitment message posted on each of the three transplant support group pages, (2) textual public recruitment message to provide information to those people who might not be in a transplant support group, and (3) paid Facebook advertisement messages that

appeared publicly in a space determined by Facebook. All messages and textual content were written using a seventh to eighth grade reading level (Gordon et al., 2012). The readability levels of the text messages were evaluated using the Simple Measure of Gobbledygook (SMOG; Online-Utility.org, n.d.) and the Flesch Kincaid Grade Level tools built into Microsoft Word 2013 (Kandula & Zeng-Treitler, 2008; McGee, 2010; Mcinnes, & Haglund, 2011; Walsh & Volsko, 2008). The average Flesch Kincaid Grade Level and SMOG index scores for the messages were eighth grade and seventh grade, 7.3), respectively.

The PI wrote the recruitment messages and textual content on the Facebook study page (Appendix J) based on the concept of social exchange (Andrews, Nonnecke, & Preece, 2007; Dillman et al., 2014; McPeake et al., 2014), which is that people feel motivated and needed when they are asked for help and advice only they can provide. To motivate potential participants to respond to surveys, experts suggest asking interesting questions, asking for participants' advice, telling potential participants how the survey results will be useful, informing potential participants that only a limited number of people may participate in the study, providing incentives, and sharing a summary of the study results with survey respondents (Andrews et al., 2007; Dillman et al., 2014). Knowing their help can contribute may be another motivating factor (Dillman et al., 2014; Laguilles, Williams, & Saunders, 2011). Confidentiality and privacy concerns regarding a Web-based survey may be a reason for people not to take a survey (Andrews et al., 2007). Therefore, each recruitment message included text such as "no personally identifiable information will be asked or collected."

Strategies to Prevent Survey Non-response and Drop-out

A lengthy survey could be burdensome to respondents and result in high non-response and drop-out rates (Dillman et al., 2014; Galesic & Bosnjak, 2009). The investigator employed strategies in this survey that have been found to be effective in increasing response rates and preventing respondents from quitting the survey prematurely: ordering of survey questions, visual presentation of questions and survey design, offering an incentive, and sending survey reminders (Dillman et al., 2014; Galesic, 2006; McPeake et al., 2014; Van Mol, 2017).

Ordering of survey questions. This study's survey incorporated eight sections that include six scales with a total of 125 questions; therefore, survey fatigue could be an issue. Survey fatigue occurs when respondents perceive that excessive time and effort are involved in completing a survey (Porter, Whitcomb, & Weitzer, 2004). They may rush through the survey, quit the survey, or avoid survey sub-questions by proving untruthful responses to reduce fatigue (Rolstad, Adler, & Rydén, 2011). The investigator thus arranged the order of scales according to their level of importance to the study. The sequence of the scales/survey questions was the KT-SM scale, the PAM, the SEMCD 6-item scale, the 25-item KT questionnaire, a patient survey form, a medical history review form, and the self-administered comorbidity questionnaire (SCQ).

Visual presentation of questions and survey design. All text was set in black Arial font (Chaparro, Bernard, Mills, Peterson, & Storrer, 2001; Dillman et al., 2014). An existing font size adjustment button located at the top right of the first survey page allowed respondents to change the font size if they desired. There are two common types of survey designs used in online surveys: scrolling design, in which questions are

presented on one page, and paging design, in which questions are presented as separate pages without scrolling. The PI selected a scrolling design after considering the survey length and the different response formats of each scale. For this study, each page represented one survey questionnaire, so the scrolling design only created six survey pages. The page number displayed on the screen so that respondents were able to see their progress in the survey along with the total number of pages (e.g., 5/6; Crawford, McCabe, & Pope, 2005; Dillman et al., 2014; Peytchev, Couper, McCabe, & Crawford, 2006). The PI realized that item non-response rate could be potentially higher in the scrolling design; therefore, only surveys with less than 10% non-response items were included in the study. To avoid survey fatigue, all participants could save survey progress and return to finish using a code generated by the REDCap system (Akard et al., 2015).

Offering an incentive. Previous studies have shown that both lottery-based incentives and guaranteed incentives such as a gift card have a positive effect on online survey response rates and response quality. To be more specific, any monetary incentive, for example, a high-probability lottery with a small prize or a low-probability lottery with a large prize, increases the web survey response rate compared to no incentive. However, a guaranteed incentive has the best impact on response rate (Berk, 2012; Funkhouser et al., 2017; Halpern et al., 2011; McCluskey & Topping, 2011; Ziegenfuss, Niederhauser, Kallmes, & Beebe, 2013). Therefore, the investigator emailed respondents who submitted completed surveys a $5 electronic Amazon gift card.

Sending survey reminders. Email reminders boost online survey response rates from 42% to 62% after two email reminders and increase 1% each time for third and fourth reminders (McPeake et al., 2014; Toledo et al., 2015). Dillman et al. (2014)

suggest sending multiple email reminders in case the original email is sent to the spam (i.e., non-requested, junk electronic mail) mail folder. It is necessary to vary the content of each email because sending the same email content repeatedly is unlikely to convince people to respond, and there is a high possibility that repeated similar emails will be sent to the spam mail folder. Janke (2014) found that mentioning the incentive in the email subject line may increase the response rate. Therefore, the investigator wrote four survey email reminders with different subject lines based on Dillman et al.'s (2014) examples of email contacts and Janke's suggestions (Appendix M). A link to the survey was embedded in the email for convenient access to the survey (McPeake et al., 2014). Eligible participants who did not complete the full survey within seven days received the link, and a second email reminder was sent at 7 a.m. on the following Monday through the REDCap system (McPeake et al., 2014; Toledo et al., 2015). However, only two reminders were sent to non-respondents because REDCap had a relative complex procedure to resume an incomplete survey, and data collection was shorter than anticipated.

Enrollment

Regardless of the location from where participants were recruited, they each followed the embedded link to be directed to the study information page and an eligibility screening page located within the REDCap system. Each participant was asked to read the study information sheet attached to the REDCap page. By clicking the "yes" button, participants agreed that they had read the study information sheet. They were then automatically directed to the screening page.

There is a major concern when using an online survey that respondents may misrepresent themselves, meaning that participants are not eligible but present themselves as being eligible. This issue is linked to low survey quality (Al Baghal & Lynn, 2015; Dillman et al., 2014; Pedersen et al., 2015; Shropshire, Hawdon, & Witte, 2009). Therefore, the PI asked each potential participant to answer four screening questions (Appendix N) as suggested by Kramer and colleagues (2014) to ensure that they have *insider knowledge*. In addition, the investigator asked each potential participant where he or she learned about the study, such as through standard Facebook ads, Facebook study page, Facebook support group, a friend, or other. This also helped the PI to assess the effectiveness of each recruiting campaign (Kramer et al., 2014; Ramo et al., 2014). The participants who passed the screening questions linked immediately to the first page of the full survey. Ineligible participants received an automatic electronic message indicating they were not eligible for the study, thanking them for their time, and directing them to close their browser.

Protection of Human Subjects

The study received approval from the Indiana University–Purdue University Institutional Review Board (IUPUI IRB; Appendix O) prior to the investigator publishing the Facebook study page, purchasing standard Facebook Ads, paying to promote the study page, and collecting data. Subjects' privacy and health information were protected per Health Insurance Portability and Accountability Act (HIPAA) rules.

The investigator conducted Facebook recruitment by: (1) paying to promote the Facebook study page, (2) posting public recruitment messages on three KT support groups (total 2,081 members), and (3) using Facebook's paid advertising feature. The

IRB previewed the recruitment messages for these three recruiting sites. The messages included the study title with an image and the directions for how to take the survey, required time to complete the survey, information about the incentive, and a link to the study information sheet page and screening page. Study information included the purpose of the study and the participants' right to not answer survey questions and to terminate participation at any time without consequences. Participants had to read the information sheet and click the agree button to start the eligibility screening section.

The risks to participating subjects were minimal; however, answering questions regarding post-KT care may evoke some uncomfortable feelings, especially if participants do not maintain a healthy lifestyle or do not always comply with their transplant doctor's recommendations. The messages included the PI's contact information so that participants could reach the researcher via Facebook message, email, and/or phone calls Monday through Friday during business hours if they had any concerns or questions regarding the study.

Data Collection

A REDCap survey was used to collect data electronically as well as store project-specific data. REDCap is a secure application that can export survey data to common statistical packages, eliminating the need for manual data entry (Akard et al., 2015; Harris et al., 2009; Patridge & Bardyn, 2018; Wong, Captur et al., 2014). A data management professional conducted a pilot test with 10 artificial data sets prior to official data collection to ensure that the survey tool functioned without flaws. The survey questionnaire consisted of eight sections: (1) study information page (Appendix J) and eligibility screening questions (Appendix N); (2) the post KT-SM scale (Appendix P);

(3) the 13-item PAM (Hibbard et al., 2005; Appendix Q); (4) the SEMCD 6-item scale (Lorig et al., 2001; Appendix G); (5) the 25-item KTQ-25 (Laupacis et al., 1993; Appendix H); (6) demographic information collected using a patient survey form (Appendix B); and (7) clinical data collected using a medical history review form (Appendix C); the SCQ (Sangha, Stucki, Liang, Fossel, & Katz, 2003; Appendix D); (8) thank-you messages (Appendix L). Data were collected at a single point in time through a self-administered REDCap online survey. A total of 153 completed and useable surveys were obtained.

Measures

The main purpose of this study was to test the reliability and validity of a newly developed 29-item post-KT-SM scale. Self-efficacy, patient activation, HRQoL, comorbidities, and demographic data were measured in this study to describe the sample and test for the validity of post-KT SM. The sections that follow provide detailed descriptions of the instruments used in this study. Permission to use the PAM (Figure A-2), KTQ-25 (Figure A-3), and SCQ (Figure A-4) were obtained prior to data collection. The SEMCD 6-item scale is free to use without obtaining permission.

Mediators: Post-KT SM, Self-Efficacy, & Patient Activation

Post-KT SM is defined conceptually as the range of behaviors patients perform in managing their own care, including ways they follow prescribed post-transplant treatment regimens, promote their own health, prevent health deterioration, and preserve graft function (Berger, 2014; Gordon et al., 2009; Haspeslagh et al., 2013; Kasiske et al., 2009). To be more specific, KT SM includes adherence to the post-transplant IS medication treatment regimen; maintaining a healthy lifestyle including regular exercise,

proper diet, and weight management; protecting the new kidney by self-monitoring allograft function and infection prophylaxis; and skin cancer precautions (Gordon, Prohaska, Siminoff, Minich, & Sehgal, 2005; Haspeslagh et al., 2013; Kasiske et al., 2009; Schäfer-Keller et al., 2008).

Development of the Post-KT SM Scale

Initial item generation. The development of the KT-SM was guided by DeVellis' (2012) eight-step scale development method. The investigator generated the initial items based on the conceptual definition (SM), the principal investigator's (PI) clinical experience, careful review of the literature, KT practice guidelines (evidenced-based medicine), and patient education information (Kasiske et al., 2009; Takahashi, Hu, & Bostom, 2018). The first item pool comprised 40 items focused on medication management, diet management, lifestyle modification, and kidney function and infection surveillance. Each was rated using a 5-point Likert-type scale (see Appendix P): 1 (*strongly disagree*), 2 (*disagree*), 3 (*neutral*) 4 (*agree*), and 5 (*strongly agree*).

Face validity. To pre-test the items and evaluate face validity, the investigator recruited six participants from a KT clinic at a university hospital in the U.S. Midwest between March and May of 2014. Cognitive interviews were conducted with three female and three male adult KT recipients to ensure clarity of survey questions and to obtain feedback and comments. The PI developed probing questions based on the questionnaires and using the check list created by Willis (2004) as guidance, such as, "What does the phrase 'change the number of pills' mean in this question?" and "What does it mean to you to change the antirejection pill dose?" Overall, participants agreed that the items

were easy to understand and answer, but there were some feedback and comments on wording, items that might not apply to their condition, or additional items suggested by participants.

In the KT-SM item pool, interviewees found the terms *side-effect*, *NSAIDS*, and *low-cholesterol food* confusing and suggested avoiding abbreviations and providing examples that would help respondents to answer the questions. In addition, none of the participants knew the difference between low-cholesterol food and a low-fat diet; therefore, the item "I eat a low cholesterol diet" was removed. In the graft function monitoring section, "I take my blood pressure every day" and "I take my temperature everyday" were only relevant depending on an individual's post-transplant condition, so adding "as needed" or "as the doctor instructed" was appropriate. The items on the KT-SM were modified and revised based on participants' feedback and suggestions as presented in Appendix E. A total of 38 items were generated in the second draft.

Content validity. To develop a high-quality instrument and to enhance the construct validity, evaluating the content validity of a scale is an essential step in ensuring that a scale has an adequate sample of items representing the construct of interest (Polit & Beck, 2006; Polit, Beck, & Owen, 2007; Wynd, Schmidt, & Schaefer, 2003). Lynn (1986) suggested that when an instrument is being developed in a highly specialized field, a minimum of three content experts should review it. The final expert panel in this study consisted of four experts: three were doctoral-level experts, two of whom are nurse scientists whose research focuses on KT behavioral change and the other a public health researcher whose research focuses on KT self-care and instrument

development. The fourth expert was a coordinator who has worked in a university KT program for more than 10 years.

The four specialists who agreed to serve as content experts for the CVI validation process were sent a cover letter, a conceptual definition of post-KT-SM, the KT-SM scale, and instructions for evaluating the instruments as suggested by McKenzie, Wood, Kotecki, Clark, and Brey (1999). The experts were asked to evaluate each item of the KT-SM for representativeness on a 4-point scale as follows: 1 (*not relevant*), 2 (*slightly relevant, the item needs major revision*), 3 (*moderately relevant, item needs minor revision*), and 4 (*highly relevant*). According to Lynn (1986), for an expert panel of fewer than six reviewers, the single item CVI must be one. After removing 11 items with low CVI, the CVI for the final version of the 29-item KT-SM was 0.931 (Appendix F).

Operational definition of KT-SM. The 29-item KT-SM was used to measure KT recipients' post-transplant SM behavior in five domains: medication management (seven items), CV risk reduction (six items), graft monitoring (six items), infection prophylaxis (six items), and skin cancer prevention (four items). Items were scored on a 5-point Likert-type scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). Scores were summed for a total score and for single domain scores. Higher scores indicated that the KT recipients engaged in the desired post-transplant SM behaviors.

Patient activation. Patient activation is defined conceptually as the level of a patient's active engagement in his or her own care and the knowledge, skill, and confidence the patient has about his or her ability to improve and maintain health, collaborate with healthcare providers, make decisions, and seek appropriate care (Hibbard et al., 2004; Shively et al., 2013; Smith et al., 2013). The PAM-13 is used to

assess participants' knowledge, skills, and confidence that are necessary to self-manage a chronic condition (Hibbard, Mahoney, Stock, & Tusler, 2007). The PAM-13 is a 4-point scale of 1 (*disagree strongly*), 2 (*disagree*), 3 (*agree*), 4 (*agree strongly*), or 5 (*not applicable*). The final score ranges from 0–100 and can be categorized into four levels. Level 1 contains scores ≤ 47.0 and indicates low knowledge and confidence levels and poor adherence. Level 2 (47.1–55.1) indicates that individuals have some knowledge but are struggling to act. People at level 3 (55.2–67.0) are acting and have started building SM skills. Level 4 (≥ 67.1) individuals have adapted to new health behaviors (Greene & Hibbard, 2012).

Psychometric testing of the PAM-13 has been conducted in various study populations including an employer-based health program ($N = 625$), adults with multiple sclerosis ($N = 199$), elderly heart failure patients ($N = 21$), and older adults with multiple chronic conditions ($N = 855$). The internal consistency for the PAM-13 has been satisfactory in these studies, with Cronbach's alphas ranging from 0.87–0.9 (Evangelista et al., 2015; Fowles et al., 2009; Prey et al., 2016; Skolasky et al., 2011; Stepleman et al., 2010). Construct validity has been supported by positive associations among patient activation and other theoretically important constructs. For example, Evangelista et al. (2015) found positive associations among increased patient activation ($r = 0.658$, $p < .0001$), self-care maintenance ($r = 0.335$, $p = 0.033$) and overall quality of life ($r = 0.329$, $p = 0.35$).

The average score for PAM-13 in this study's sample ($N = 153$) was 77.89 ± 15.71, with a median of 77 and a range between 9 and 100. Overall, more than 94% of kidney recipients were at level 3 (26.1%) or 4 (68%), which means they were acting in

self-managing their post-transplant care or have adapted to post-transplant SM behavior and are trying to maintain it (see Table 1).

Table 1

Mean, Standard Deviation, Range, and Mode of PAM-13

Scale	*n* (%)	*M(SD)*	Range	Median	Mode (%)
PAM-13 score	153(100)	77.89(15.71)	9–100	77.7	4 (68%)
PAM level					
Level 1	3(2%)				
Level 2	3(2%)				
Level 3	40(26.7%)				
Level 4	104(69.3%)				

As shown in Table 2, the reliability coefficient alpha for the PAM-13 was .90, and corrected item-to-total correlations ranged between .50 and .73. The mean inter-item correlation was .45, indicating adequate internal consistency (DeVellis, 2012). This is the first study to test the PAM-13 in the KT population, so there are no empirical study results available for comparison; therefore, further study on item reliability with a larger sample size may be needed.

Table 2

Internal Consistency Reliability for the 13-Item PAM

Scale	*Mean* (*SD*)	Cronbach's Alpha	Alpha if Item Deleted	Mean Inter-Item Correlation	Range of Item to Total Correlation
PAM-13	77.89 (15.71)	.90	.90	.45	.50-.73

Note. $N = 153$.

Self-efficacy. In this study, self-efficacy is conceptually defined as an individual's confidence in his or her own capability to successfully perform given tasks and achieve a goal (Bandura, 1997; Bodenheimer et al., 2002). Patients with high self-efficacy engage more in SM behaviors and have better physical function and higher perceived HRQoL (De Pasquale et al., 2014; Mersal & Aly, 2014; Weng et al., 2010). Self-efficacy was measured with the 6-item SEMCD scale. The SEMCD incorporates the domains of symptom control, physical function, emotional function, and communication with physicians, which are common problems for people with chronic conditions (Lorig et al., 2001). The SEMCD (Appendix H) includes questions such as: "How confident are you that you can keep from getting discouraged when nothing you do seems to make any difference?" Responses range from 1 (*Not at all confident*) to 10 (*Totally confident*). Possible scores range from 6 to 60. A lower score indicates that the patient is less confident in self-managing post-transplant care.

Internal consistency reliability of the SEMCD has been supported in chronic kidney disease, arthritis, Parkinson's disease, systemic sclerosis, and people with chronic disease, with Cronbach's alphas of .81 to .95 (Johnson et al., 2016; Lorig et al., 2001; Riehm et al., 2016; Ritter & Lorig, 2014; Dal Bello-Haas, Klassen, Sheppard, & Metcalfe, (2011). Concurrent validity was demonstrated with a positive correlation between the French version of the SEMCD and the Health Education Impact Questionnaire ($r = 0.49$, 95% CI, $p < 0.01$; Hudon, 2014). Convergent construct validity between the German version SEMCD and the German General Self-Efficacy Scale was supported by Spearman rank correlation ($r =. 578$, $p < .001$). The result of principal component analysis also confirmed that the SEMCD is a uni-dimensional scale (Freund,

Gensichen, Goetz, Szecsenyi, & Mahler, 2013). Similarly, Riehm and colleagues (2016) conducted a psychometric test of the SEMCD with a systemic sclerosis population (n = 553) in the U.S., Canada, and the U.K., and the confirmatory factor analysis results supported its unidimensionality. Convergent construct validity has been supported and showed significant positive correlations between the SEMCD and the psychological and physical functioning subscales of the Patient Reported Outcomes Measurement Information System (PROMIS; r = 0.48 to 0.67, $p < 0.001$) and negative correlations between the 8-item Patient Health Questionnaire (r = -.48 to -.64, $p < 0.001$) and the Health Assessment Questionnaire Disability Index (r = -.57, $p < 0.001$).

The average score on the SEMCD in the present study was 7.44 ± 1.8 (*SD*) and the median was 7.67, with a range from 2 to 10. Internal consistency reliability of the SEMCD (Cronbach's alpha) was .93, demonstrating that the scale has good internal consistency. The mean inter-item correlation was .68, with a range from .56 to .81. The corrected item-to-total correlation ranged between .74 and .8 (Table 3). This study's results shows no differences from previously reported findings.

Table 3.

Internal Consistency Reliability for 6-Item SEMCD

Scale	*Mean* (*SD*)	Cronbach's Alpha	Range of Alpha if Item Deleted	Mean Inter-Item Correlation and Range	Range of Item to Total Correlation
SEMCD	7.44 (1.80)	.93	.90–.92	.68 (.56–.81)	.74–.80

Note. N = 153.

Outcome: HRQoL

An individual's subjective experiences of satisfaction with his or her physical, emotional, and social functioning and well-being is conceptually defined as HRQoL (Maglakelidze et al., 2011; Molnar-Varga et al., 2011; Shumaker et al., 1997). Compared to dialysis patients and ESRD patients, KT recipients experience higher HRQoL. Nevertheless, a KT may not fully restore KT recipients' level of HRQoL to that of the general population. The requirement to take lifelong IS medications and side effects from long-term IS treatment are tied to decreased HRQoL (Gentile et al., 2013; Morales, Varo, & Lázaro, 2012). Therefore, a KT-specific HRQoL scale was needed for this study.

This study used the 25-item KTQ-25 developed by Laupacis and colleagues (1993) to measure HRQoL. Questions on the KTQ-25 are measured with a 7-point Likert-type scale and incorporate five disease-specific dimensions: physical symptoms, fatigue, appearance, uncertainty/fear, and emotion (Appendix H). Scores are summed for a total score and for five single domain scores. Higher summed scores indicate better quality of life (Kosinski, Ware, Turner-Bowker, & Gandek, 2007).

The reported mean scores on the KTQ-25 from previous literature were as follows: physical symptoms, 4.5–5.7; fatigue, 4.7–5.4; uncertainty/fear, 4.5–5.4; appearance, 5.7–6.8; and emotion, 4.8–5.4 (Chisholm-Burns, Erickson, Spivey, Gruessner, & Kaplan, 2011; Neipp et al., 2006; Tayebi et al., 2012). Internal consistency reliability for the total scale has been reported to be .80 to .95 in previous studies (Neipp et al., 2006; Rostami, Tavallaii, Jahani, & Einollahi, 2011; Tayebi et al., 2010; Tayebi et al., 2012). The reported Cronbach's alpha for physical symptoms, fatigue, uncertainty/fear, appearance, and emotion subscales ranged from .82–.93, .81–.90,

.63–.81, .72–.62, and .82–.95 respectively (Chisholm-Burns et al., 2011; Neipp et al., 2006; Rostami et al., 2011; Tayebi et al., 2010; Tayebi et al., 2012).

Concurrent validity of the SF-12 Health Survey version 2 mental component summary and physical component summary) and the KTQ-25 has been confirmed in the adult U.S. KT population. Mental component summary (Chisholm-Burns et al., 2011) was positively correlated with KTQ-25 subscales ($p < .01$): physical symptoms ($r = .43$), fatigue ($r = .48$), uncertainty/fear ($r = .33$), emotion ($r = .47$), and appearance ($r = .28$). Physical component summary was positively correlated with subscales ($p < .05$) physical symptoms ($r = .43$), fatigue ($r = .42$), and uncertainty/fear ($r = .2$).

As shown in Table 4, mean scores for the total and the five subscales (physical symptoms, fatigue, uncertainty/fear, appearance, and emotion) in this study were: 4.83, 4.57, 4.62, 5.71, and 4.97, respectively. Internal consistency reliability scores for the five subscales of the KTQ-25 were .85, .95, .76, .72, and .89, respectively, with an alpha value of .79 for the total scale. This study's findings are consistent with studies in the U.S. KT population that found that Cronbach's alpha is lower in the uncertainty/fear and physical appearance subscales but still within acceptable range (Chisholm-Burns et al., 2011).

Table 4

Internal Consistency Reliability of KTQ-25 and 5 Subscales

Scale/ Subscale	*M* (*SD*)	Cron-bach's Alpha	Range of Alpha if Item Deleted	Mean Inter-Item Correlation	Range of Item to Total Correlation
KTQ-total	4.94 (1.08)	.94	.89–.91	.39	.28–.74
Physical	4.83 (1.63)	.92	.89–.91	.65	.69–.82
Fatigue	4.57 (1.56)	.95	.93–.95	.79	.78–.90

Table continues

Uncertainty	4.62 (1.36)	.76	.62–.86	.47	.29–.73
Appearance	5.71 (1.15)	.72	.49–.74	.38	.36–.74
Emotion	4.97 (1.26)	.89	.86–.89	.58	.62–.80

Note. N =153. 26 respondents reported no physical symptoms.

Antecedents: Comorbidities and Demographic Characteristics

Comorbidities refer to one or more chronic diseases that coexist with the index disease. The comorbidities could be post-KT-related or pre-existing chronic disease (Hollisaaz et al., 2007; Valderas et al., 2009). The number of comorbid diseases was measured using the SCQ. The SCQ consists of yes/no questions about 12 common medical conditions and 3 additional open-ended options that allow individuals to provide diseases not on the SCQ list (Kyranou et al., 2013; Sangha et al., 2003; Sridharan et al., 2014). An individual can obtain three points for each of 12 listed conditions and up to 3 additional write-in conditions (one point each for presence of the disease, receiving treatment for that disease, and physical limitation due to disease; Kyranou et al., 2013; Sangha et al., 2003; Sridharan et al., 2014). The target population for this study was KT recipients with functional allograft; hence, the item *kidney disease* was removed (Sridharan et al., 2014). Therefore, the maximum scores ranged from 33–42 points.

The reliability and validity of the SCQ have been confirmed in the literature. The test-retest reliability was moderate to high for most items, ranging from kappa = .40–.90, which demonstrates adequate internal consistency reliability (Sangha et al., 2003). Construct validity was assessed by Spearman correlation between the SCQ and the CCI and was Spearman r = .55 (Sangha et al., 2003). Predictive validity was assessed by computing the Spearman correlation between the SCQ and the SF-36; the physical component score was r = 0. 35, which was higher than the correlation between the CCI and SF-36 (r = 0. 23; Moltó & Dougados, 2014; Sangha et al., 2003; Sridharan et al.,

2014). Mean score for the SCQ in this sample was 4.94 (*SD* = 4.52; median = 4), and the average number of comorbidities was 2.46 (*SD* = 1.86), ranging between 0 and 12. Table 5 shows the frequencies of comorbidities. The top three reported comorbidities were high blood pressure (60.8%), back pain (30.1%), and diabetes (25.7%). Frequently reported diseases not on the SCQ were systematic lupus erythematosus and hypothyroidism. The reported incidence rate of diabetes and hypertension has been reported in KT literature to range from 4%–30% and 60%–90%, respectively (Kislikova et al., 2015; Pourmand et al., 2015; Sarno et al., 2012; Seeman, 2009; Shah et al., 2006; Wu et al., 2005). This study's results were consistent with previous findings except for back pain.

Table 5

Number of Comorbidities Reported

Comorbidity	*n*	*f* (%)
High Blood Pressure	153	93 (60.8)
Receive treatment		89 (95.7)
Limit activities		6 (6.5)
Back pain	153	46 (30.1)
Receive treatment		11(23.9)
Limit activities		28 (60.9)
Diabetes	152	39 (25.7)
Receive treatment		35 (92.1)
Limit activities		7 (18.4)
Heart disease	152	18 (11.8)
Receive treatment		17 (94.4)
Limit activities		8 (44)
Lung disease	152	9 (5.9)
Receive treatment		6 (66.7)
Limit activities		5 (55.6)

Table continues

Ulcer or stomach disease	152	11 (7.2)
Receive treatment		10 (90.9)
Limit activities		3 (30)
Liver disease	152	7 (4.6)
Receive treatment		2 (28.6)
Limit activities		3 (42.9)
Anemia or other blood disease	152	24 (15.8)
Receive treatment		14 (58.3)
Limit activities		6 (25)
Cancer	149	10 (6.6)
Receive treatment		6 (66.7)
Limit activities		5 (55.6)
Depression	150	33 (22)
Receive treatment		20 (60.6)
Limit activities		17(51.5)
Osteoarthritis or degenerative arthritis	151	25 (16.6)
Receive treatment		8 (32)
Limit activities		18 (72)
Rheumatoid arthritis	151	4 (2.6)
Receive treatment		1 (25)
Limit activities		0
Other medical problem 1	153	113 (73.9)
Receive treatment		23 (56.1)
Other medical problem 2	152	10 (62.5)
Receive treatment		6 (37.5)
Limit activities		0
Other medical problem 3		8 (5.3)
Receive treatment		6 (3.97)
Limit activities		2 (1.4)
SLE		8 (5.3)
Thyroid problem		6 (3.97)
Gout		2 (1.4)

Demographic Characteristics

Demographics are the characteristics of the study population, including age, race, gender, marital status, and education (Kane & Radosevich, 2010). Demographic data were collected to describe the sample and used to examine whether poor SM behaviors, low self-efficacy, low patient activation levels, and poor HRQoL are associated with certain demographic characteristics. The demographic data for this study come from an

investigator-developed patient survey form (see Appendix B). It is a self-administered, categorical, nominal, and open-ended questionnaire. Gender was collected with dichotomous response. Age was collected using an open-ended question. Other information such as race, marital status, employment status, and education were collected using categorical responses.

Data Management and Data Cleaning

Data analysis for each hypothesis was conducted using IBM SPSS version 24.0 statistical software. The level of significance for this study was set at $p < 0.05$. Data from REDCap were directly exported to .csv (comma separated variables) files; no hand entry of data was required. To ensure data quality, REDCap online survey and data entry forms were co-built and maintained by data management professionals from the biostatistics department at IUPUI. The data management professional conducted a pilot test of the REDCap survey system with 10 artificial data sets before the study started. Missing data were managed per recommendations from Tabachnick and Fidell (2012). In addition, surveys with more than 10% unanswered items were eliminated from the analysis. Descriptive statistics, scatterplots, and histograms were checked for distributions and outliers on all collected variables (Van den Broeck, Cunningham, Eeckels, & Herbst, 2005).

Descriptive statistics were performed to check missing values, means, standard deviations, and out-of-range values. Nominal variables were described as frequencies and percentages, while interval data were averaged as means and standard deviations. All data were analyzed for normality, linearity, and homoscedasticity. The analyses conducted to meet each study aim are described as follows.

Aim 1: Examine the content validity of the KT-SM scale.

H_1: The KT-SM scale will demonstrate evidence of a CVI of 0.9 or greater for individual items and for the overall scale based on a review by four content experts of construct definition, item relevance, wording clarity, and item appropriateness.

There are two recommended methods to determine content validity: the content validity ratio (CVR) proposed by Lawshe (1975) and Lynn's (1986) CVI. Lynn's method was used to assess the content validity of the newly developed 40-item KT-SM scale. Content relevance is ranked as 1 (*not relevant*), 2 (*slightly relevant with major revisions*), 3 (*quite relevant with minor revisions*), or 4 (*highly relevant*). Acceptable CVI score ranges of the items depend on the number of reviewers (DeVon et al., 2007). In this case, agreement about the relevance of each item must be at least 3 (*quite relevant*) or 4 (*highly relevant*) on average among the experts. The item CVI is a ratio that is calculated, based on the sum of the scores for each item divided by the number of experts. For example, if the expert panel ranked item 12 as 3, 4, 3, and 4, all four experts agree the item content is relevant but may require a minor wording revision so the CVI is 1 (number of agreement = 4/4 experts).

Aim 2: Estimate the reliability of a new instrument, the Kidney Transplant SM scale (KT-SM), among adult KT recipients.

H_2. The KT-SM scale will have adequate internal consistency coefficient as evidenced by corrected item-to-total correlations, mean inter-item correlations of greater than or equal to .30, and Cronbach's alpha greater than or equal to .70 among KT recipients aged 18 or greater.

Inter-item correlation, item-total correlation, and Cronbach's alpha were estimated to check item homogeneity and internal consistency reliability of the final version of the KT-SM scale.

Aim 3: Estimate construct validity of the KT-SM scale through EFA.

H_3: The EFA results will support that the KT-SM scale is a multidimensional scale with more than one factor extracted, and items within each factor will have factor loading values greater or equal to .40.

To address H_3, three assumptions must be met: (1) there must be no multicollinearity, (2) the data must be factorable, and (3) the sample size must be adequate. First, the investigator inspected correlation matrices to examine whether the values of the correlation coefficients were greater than .25 and less than .90 (Pett et al., 2003; Polit, 2010). The second diagnostic test used to evaluate factorability in the present dataset was Bartlett's Test of Sphericity, which tests the null hypothesis that variables in the matrices are orthogonal. Failure to reject the null hypothesis indicates that factor analysis is not amenable in this sample (Polit, 2010). Lastly, the Kaiser-Meyer-Olkin (KMO) test of sampling adequacy was computed to assess how suitable the sample size is for factor analysis; KMO scores greater than 0.5 are considered acceptable.

To determine the underlying factor structure of the KT-SM scale, factor extraction was conducted by EFA using principal axis factoring (PAF) with varimax rotation (Pett et al., 2003; Netemeyer et al., 2003). The number of factors to be extracted was determined by the eigenvalues-greater-than-1 rule and the scree test (Tabachnick & Fidell, 2012). Items with factors loading less than .40 and communality less than .30 were removed. Item communality is "the total amount of variance in each item that is

explained by the extracted components" (Pett et al., 2003, p. 100). Communalities greater than .30 are preferable (Costello & Osborne, 2005).

Aim 4: Estimate construct validity of the Kidney Transplant SM (KT-SM) scale guided by the conceptual model by exploring relationships between the KT-SM scale and the SEMCD scale, the PAM, and the KTQ-25.

H_4: Controlling for demographic and clinical variables, a significant amount of variance in the KT-SM scale will be explained by self-efficacy and patient activation.

H_5: Controlling for demographic and clinical variables, a significant amount of variance in HRQoL will be explained by self-efficacy, patient activation, and KT-SM behavior.

H_6: Criterion-related validity will be supported as the 16-item KT-SM total scale and five domain scales are statistically significantly correlated with the PAM-13, SEMCD, and KTQ-25 and 5 subscales.

To determine the strength and direction of each proposed theoretical relationship in the framework, Pearson correlation coefficient/Spearman correlation coefficient was computed for the variables of self-efficacy, patient activation, KT SM behavior, and HRQoL. To address H_4 and H_5, the adapted KTSM framework shown in Figure 1 was used to assign order of entry of study variables; therefore, sequential multiple regression was employed to assess construct validity (Tabachnick & Fidell, 2012). In the first step, the investigator entered demographic and clinical variables into the regression equation to control their effect on the independent variables. According to Tabachnick and Fidell (2012), variables that are theoretically important could be entered in the early steps;

therefore, self-efficacy was added first to the regression equation and patient activation in the second step. To test H_5, KT SM was entered in the last step.

To test H_5 the investigator entered variables into a regression equation in the following sequence: KT SM behavior, patient activation, and self-efficacy. HRQoL was added into the equation last.

H_6 is about criterion validity and will be supported with statistically significant intercorrelation among the scores of the KT-SM total scale and its five domain scales, PAM-13, SEMCD, and KTQ-25 and its five subscales.

Summary

Chapter Three presented the methodology used in this study including participant eligibility criteria, the study design, methods and procedures used for recruitment, and concluded with the presentation of the results of the cognitive review and content validity scores of the new investigator-developed KT-SM scale. The sequential regression analysis results showed that self-efficacy is a strong predictor of scores on the KTQ-25 overall and its five subscales, but the KT-SM total score and four of the five domain scores and the PAM-13 did not reach statistical significance in predicting the KTQ-25 score. Therefore, this discussion focused only on results pertaining to the KT-SM scale.

The following chapter will present the study results beginning with a description of the data collection methods used and concluding with the results pertaining to each specific aim and hypothesis.

CHAPTER FOUR

RESULTS

This chapter consists of four sections. The first section begins with a description of the data collection methods. The second section describes the data cleaning procedure, including specific decision rules for keeping or deleting a completed online survey. A description of the sample is provided in the third section. A description of the study variables and the results pertaining to each specific aim and hypothesis are presented in the last section.

Data Collection Methods

A total of 538 respondents visited the KT study information page (Appendix J) from May 10, 2016, to June 9, 2016. Of these, 292 (54.28%) read the study information material and submitted valid email addresses. By clicking the acknowledge button, respondents agreed that they were fully informed about the study and agreed to participate. Twenty-seven respondents declined, as indicated by not clicking the acknowledge button, leaving 265 (90.75%) respondents who agreed to participate in the study and be screened for eligibility. Of these, 210 participants (79%) passed the screening question and took the full survey (Figure 2).

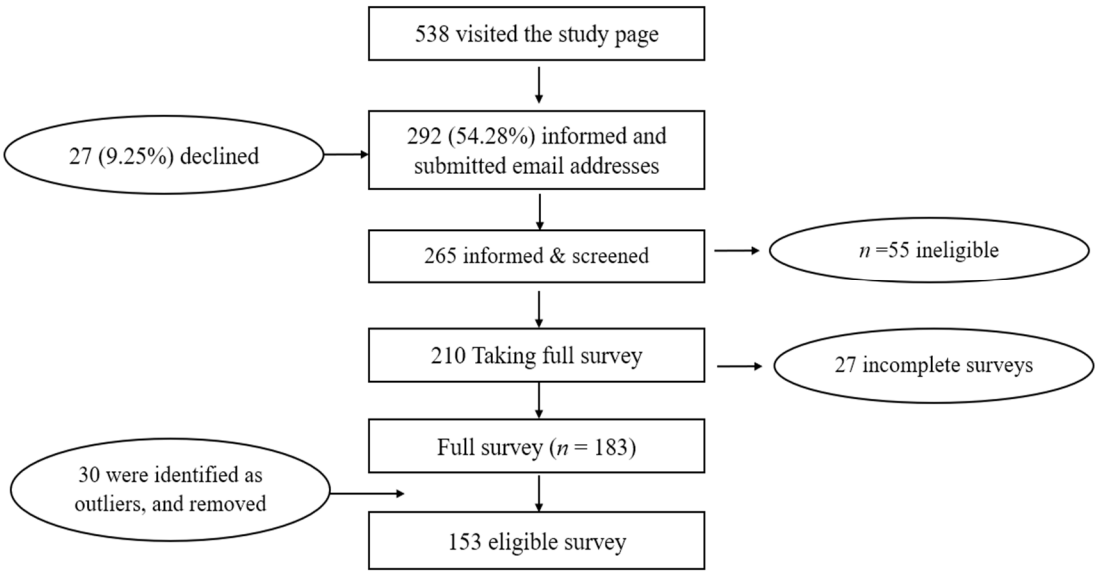

Figure 2. Recruitment process.

Data Cleaning Procedures

Data were collected using a self-administered REDCap online survey. All data were exported directly from the REDCap survey project platform into a Microsoft Excel file and analyzed in SPSS 24.0 software. To ensure online survey data quality, surveys were first screened for missing items, multiple submissions, and out-of-range survey taking time. Three decision rules were applied in determining whether to keep or delete a completed survey. First, if more than 10% of item responses were missing, the entire survey was deleted. After a careful investigation of the 210 submitted surveys for the number and patterns of missing items, 27 were deleted because more than 10% of the item responses were missing, leaving 183 surveys (Figure 2). To prevent multiple submissions, each respondent could use only one email address. Email addresses were searched for duplication using SPSS frequencies, and no duplicate email addresses were identified. Finally, the time spent taking the survey was examined for extreme values; rationales for examining online survey response time are discussed in detail in the

sections that follow (Brandon, Long, Loraas, Mueller-Phillips, & Vansant, 2013; Maniaci & Rogge, 2014; Meade & Craig, 2012; Revilla & Ochoa, 2015).

Studies have shown that online survey response time has an impact on data quality (Brandon et al., 2013; Maniaci & Rogge, 2014; Meade & Craig, 2012; Revilla & Ochoa, 2015). A short survey response time may indicate that a respondent rushed through the whole survey by selecting random answers without reading the questions and instructions. In contrast, a longer response time shows that a respondent put more cognitive effort into completing the survey, but this could also be a result of being distracted (Meade & Craig, 2012). In addition, the speed of individual processing and comprehension is different, so a speed-reader could have short response times in completing a survey (Börger, 2016; Ramsey, Thompson, McKenzie, & Rosenbaum, 2016; Revilla & Ochoa, 2015). Thus, examining surveys for the time spent in completion is a necessary step before performing statistical analyses (Maniaci & Rogge, 2014).

There is no *gold standard* for determining the acceptable length of time for completing an online survey. Meade and Craig (2012) recommended that a cutoff point must be set to eliminate those who respond to survey questions too quickly. Therefore, decisions to keep or eliminate extreme cases in this study were determined by examining descriptive statistics. Identifying outliers in the original dataset was problematic because (1) several extreme values made the distribution positively skewed, (2) there was only one single bar shown on the histogram, and (3) the box plot displayed only one single line. Therefore, a base-10 logarithmic (log 10) transformation was performed (Feng et al., 2014; Osborne, 2005; Tabachnick & Fidell, 2012), and Tukey's (1977) 1.5 * interquartile (IQR) rule was followed to eliminate outliers that impacted score mean and distribution

(Acuna & Rodriguez, 2004; Hatcher, 2013, Hoaglin, 2003; Hubert & Van der Veeken, 2008; Polit, 2010; Tabachnick & Fidell, 2012). An outlier is defined (Hatcher, 2013; Pallant, 2013) as a data value that exceeds 1.5 box-lengths from the lower quartile (Q1) or upper quartile (Q3). The values of IQR, Q1, and Q3 of the log 10-transformed data were 0.30, 0.954, and 1.255 respectively. The lower boundary and upper boundary were calculated based on the formulas Q_1 - 1.5 * IQR and Q_3 + 1.5 * IQR. The lower boundary was 0.504 (0.954 - 1.5 * 0.3), while the upper boundary was 1.705 (1.255 + 1.5 * 0.3). Data values below 0.504 or above 1.705 were identified as outliers. This means that people who took 3 minutes or fewer to complete the survey (n = 25) and those who took more than 65 minutes (n = 5) were eliminated; a total of 30 surveys were deleted, leaving 153 completed surveys available for analyses (see Figure 2).

As shown in Table 6, the shortest survey response time among the remaining 153 respondents was 4 minutes (M = 15.07; SD = 6.12), consistent with Huang and colleagues' (2012) recommended "2 seconds per item" rule for minimal survey response time. Applying this rule to the present study indicated a likely survey response time of 4.1 minutes [(2 * 123 items)/60 seconds].

Table 6

Descriptive Statistics for Average Survey Response Time

	N	*Mean* (*SD*)	Mdn	Range	Skewness	Kurtosis
Original	183	89.21(955.65)	13	1 - 12928	13.47	181.94
Outliers removed based on 1.5 * IQR rule	153	15.07(6.12)	15	4 - 43	1.35	3.21

Examining Accuracy of the Dataset

All collected data were exported directly into a Microsoft Excel file. Data entry errors should not be a concern, but means, standard deviations, and ranges were inspected for all continuous variables using univariate descriptive statistics (see Table 7).

Table 7

Mean, Standard Deviation, Range, Skewness, and Kurtosis of all Scales

Variable	*N* (%)	*M*	*SD*	Mdn	Range	Skewness	Kurtosis
PAM-13	153	77.89	15.71	77.7	91	.66	1.41
PAM-13 (if ID 44 deleted)	152	78.34	14.73	77.7	57	.22	.50
SEMCD	153	7.44	1.8	7.67	8	-.57	-.32
KTQ-physical	153*	4.83	1.63	4.83	5.50	-.21	-1.06
KTQ-fatigue	153	4.57	1.56	4.80	6.00	-.33	-.77
KTQ-fear	153	4.62	1.36	4.75	6.00	-.41	-.15
KTQ-appearance	153	5.72	1.15	6.00	4.75	-.76	-.34
KTQ-emotion	153	4.97	1.26	5.00	5.33	-.35	-.55
KT-SM-Original	153	4.27	.47	4.34	2.17	-.60	-.34
SCQ score	153	4.97	4.53	4.00	34	2.80	13.05
Squared root-SCQ	153	.63	.30	.60	1.53	.17	- .06

Note. *26 participants reported no physical symptoms. **13 reported no comorbidity.

Missing Data

A total of 153 surveys were examined for missing data. Missing data were analyzed using IBM SPSS MVA (missing values analysis) for continuous and categorical variables. The results indicated no missing values detected in the PAM-13, SEMCD scale, 29-item KT-SM scale, 25-item KTQ, and years since transplant. The amount of missing data for the rest of the continuous variables was less than 5% and was missing randomly at the item level. Missing values for the categorical variables of marital status, ethnicity, and pre-transplant dialysis were at 0.7%, 1.3%, and 0.7 %, respectively. Thus,

it was not necessary to replace missing data with means or to manage it using multiple imputation; instead, missing values were handled using SPSS's pairwise deletion for descriptive statistics, while listwise deletion was the default for multiple regression analysis (Dong & Peng, 2013; Scheffer, 2002).

Outlier and Data Normality

Outliers and data distribution were checked by inspecting the boxplot, normal P-P plot, and detrended normal Q-Q plot and assessed with analysis of skewness and kurtosis for all variables. As displayed in Table 7, there are a wide range of values for the PAM-13 and the SCQ. The investigator identified record IDs 35 and 44 as outliers for the PAM-13 and record ID 88 as an outlier for the SCQ using the IBM SPSS EXPLORE program. The skewness and kurtosis statistics of all scales depict that most variables had values fairly close to zero except for the PAM-13 and the SCQ. The zero value indicates no skewness and kurtosis in the distributions. For severely skewed data, Tabachnick and Fidell (2012) recommend transformations because transformations may normalize the skewed data, improve the validity of analysis, and act as a remedy for outlying observations.

Natural log and square root transformations were computed for the PAM-13, but there were no improvements in the distribution or kurtosis statistics. However, the skewness and kurtosis statistics of the PAM-13 decreased from -0.66 to -0.21, and from 1.41 to -0.50, respectively, after excluding the outlier record ID 44. After cautiously examining all the survey data and response patterns of record ID 44, the investigator could not eliminate the possibility that this individual respondent may simply have lower confidence in managing long-term post-transplant life. In addition, Likert-type scales

have ceiling and floor effects such that a case with a lowest point or highest point is considered to reflect reality, therefore, record ID 44 was retained. Nevertheless, the slight violation of the normality assumption should not cause any major concerns. Skewness and kurtosis values of ± 2 are within acceptable ranges for psychometric testing (Molle & Froman, 2017) when the sample size is larger than 40. Parametric statistical tests were considered appropriate for the present study, which had a sample size of 153 subjects (Ghasemi & Zahediasl, 2012; Norman, 2010; Sullivan & Artino, 2013). In addition, Norris and Aroian (2004) compared the Cronbach's alpha and the Pearson product moment correlation using original data and square root and log-transformed data; there was no difference between these data sets.

Sample Description

A sample of 153 adult KT recipients met the study criteria. Most of the 153 subjects were recruited via Facebook Ads (51%; Appendix J), and three Facebook support groups (Kidney Transplant Survivors and Donors; Kidney Transplant and Weight Loss, & Kidney Transplants; 34%). As shown in Table 8, the average patient was middle-aged, White, non-Hispanic or Latino, female, married or living with a partner, and had a college degree or higher. More than half of the subjects were working full time.

Table 8

Characteristics of Participants

	n (%)	*Mean* (*SD*)	Median	Range
Age	149 (97.4)	46.65(12.35)	47	19–78
Gender	152 (99.3)			
Female	98 (64.5)			
Male	54 (35.5)			

Table continues

Marital status	152 (99.3)
Married	88 (57.9)
Living with a partner	16 (10.5)
Never married	23(15.1)
Separated/divorced	24 (15.8)
Widowed	1 (0.7)
Race	153 (100)
White	125 (81.7)
Black/African-American	13 (8.5)
Hispanic/Latin	8 (5.2)
Asian	3 (2)
American Indian/Alaska	1 (.70)
Native	3 (2.0)
Native Hawaiian/Pacific Islander	
Education level	153
Less than high school	3 (2)
High School, diploma, or	18 (11.8)
GED	46 (30.1)
Some college	46 (30.1)
College graduate	9 (5.9)
Some graduate work	25 (16.3)
Graduate degree	4 (2.6)
Some doctoral work	2 (1.3)
Doctoral degree	
Employment	153
Employed full-time	71 (46.4)
Employed part-time	13 (8.5)
Retired	23 (15)
Unemployed	31 (20.3)
Other	
Social security disability	14 (9.2)
Student	1 (.70)
Recruiting setting	
Facebook ads	78 (51)
Three Transplant Support	52 (34)
Groups	12 (7.8)
Facebook study page	2 (1.3)
Google+	1 (.70)
Search engine	8 (5.2
A friend	

Clinical characteristics of the sample are shown in Table 9. The majority of the sample received living donor KTs. Nearly 73% of the sample reported being on dialysis

prior to transplant; of these, the average years of dialysis was 2.89. The mean years post-transplant was 7.01. The mean SCQ score was 4.94; on average, individual participants reported 2.46 comorbidities.

Table 9

Clinical Characteristics

	n (%)	*Mean* (*SD*)	Median	Range
Donor type	153			
Non-living donor	69 (45.1)			
Living donor (Related)	52 (34)			
Living donor (Non-related)	32 (20.9)			
Pre-transplant dialysis				
Yes	111 (72.5)			
No	39 (27.5)			
Years receiving dialysis	153	2.89 (3.32)	2.00	0.08–16.42
Years since transplant	145 (94.8)	6.94 (6.65)	4.50	0.83–27.83
Squared root-SCQ Score	152	1.97 (.93)	4.00	0–34
Numbers of comorbidity reported	153	2.46 (1.86)	2.00	0–12

Note. $n < 153$ indicates missing data.

Aims, Hypotheses, and Research Questions

A brief description of the item reduction process follows. Psychometric testing of a newly developed instrument is an iterative process. Forty items were included in the original KT-SM scale. Based on content validity results, 11 items were removed (Aim 1) so that the initial EFA included 29 items (Aim 3). After further testing and removal of items, the final solution included 16 items. Internal consistency reliability testing (Aim 2) was conducted on the final 16-item KT-SM scale. Construct validity testing of the relationships among KT SM, patient activation, self-efficacy, and quality of life (Aim 4) used the final 16-item instrument.

Aim 1: Examine the content validity of the KT-SM scale.

H_1: The KT-SM scale will demonstrate evidence of a CVI of 0.9 or greater for individual items and for the overall scale based on a review by four content experts of construct definition, item relevance, wording clarity, and item appropriateness.

H_1 was supported. The CVI score for the reduced 29-item KT-SM scale was .93. Initially, the KT-SM scale with a total of 40 items was mailed electronically to four content experts, whose recommendations led to 11 items with CVI scores of .50 or below being removed from the scale. For the remaining 29 items, there were 21 items with CVI = 1 and 8 items with CVI value of .75. The CVI for the total scale was .93, which was calculated based on the following formula: ((21 items * 1) + (8 items * .75)) / 29 items. A CVI value of .70 or greater is preferable (Tilden, Nelson, & May, 1990); therefore, the first hypothesis is determined to be supported. Detailed results are provided in Appendix F. Some items with CVI score of .75 were retained in the scale because they are conceptually important and are recommended by KT guidelines (Kasiske et al., 2010). Wording changes on these items were made based on comments from reviewing experts.

Aim 2: Estimate the reliability of a new instrument, the KT-SM scale, among adult KT recipients.

H_2: The KT-SM scale will have adequate internal consistency coefficient as evidenced by corrected item-to-total correlations, mean inter-item correlations of greater than or equal to .30, and Cronbach's alpha greater than or equal to .70 among KT recipients aged 18 or greater.

H_2 was supported. The item-to-total correlations for the overall final version of the 16-item KT-SM scale and 5 domains were greater than .38. The inter-item correlations for the 5 subscales ranged from .38 to .63. Cronbach's alpha for the overall scale was .84 and had a range of .70 to .83 for the five domains.

To examine the internal consistency reliability of the newly developed KT-SM scale, corrected item-to-total correlations, mean inter-item correlations, and Cronbach's alpha coefficients were estimated for the reduced 16-item scale after the EFA. These analyses were done within each dimension as the scale is multidimensional (Netemeyer et al., 2003).

Basic Item Analysis

The KT-SM scale consists of five conceptually distinct components; therefore, item statistics and reliability statistics were reported for the five subscales (Clark & Watson, 1995; DeVellis, 2012; Georgiou & Kyza, 2017; Welch, 2002): medication adherence, CV risk reduction, protecting the new kidney, ownership of post-KT care, and skin cancer prevention. Items were examined for item statistics, corrected item-to-total correlation, and alpha coefficient. Table 10 displays the item means and standard deviations. Item means for these 16 items ranged from 3.27 to 4.70, and the standard deviation ranged from .67 to 1.23. DeVellis (2012) suggests that item means should be close to the center of the possible score range; for this study, an item mean value around 3 was desirable. The results revealed that some level of ceiling effect did exist.

Table 10

Item Statistics and Item-Total Statistics for the 16-item KT-SM Domains

Domains /Item	Cronbach's alpha[a]	*Mean* (*SD*)	Mean IIC	Corrected Item-Total Correlation	SMC	Alpha if Item Deleted
Medication adherence (3 items)	.83	4.60	.62			
I take my antirejection pills as instructed by my transplant doctor		4.73 (.80)		.65	.43	.80
I call my transplant team if my antirejection pills make me sick		4.42 (.94)		.73	.54	.73
I tell my transplant doctor about problems and concerns with my antirejection pills		4.66 (.74)		.70	.50	.60
Cardiovascular risk reduction (4 items)	.70	3.56	.38			
I avoid eating sweets, fried foods and other high calorie foods most of the time		3.27 (1.08)		.64	.41	.55
I eat low fat foods like chicken, poultry, lean meats, or low-fat dairy products most of the time		3.71 (1.01)		.47	.26	.65
I read food labels most of the time		3.84 (1.17)		.45	.23	.67
I exercise at least 5 times per week		3.44 (1.23)		.42	.20	.69

Table continues

Protecting kidney (4 items)	.72	4.36	.40			
I limit alcoholic drinks to no more than one drink per day		4.68		.38	.21	.73
I call my transplant team if I gain more than 3 pounds in one day		4.18		.53	.32	.66
I call my transplant doctor if I urinate (pee) less than usual		4.22		.59	.37	.61
I call my transplant doctor when I have signs of an infection like fever, flu-like symptoms, pain on urinating or a cough		4.39		.59	.38	.62
Ownership (2 items)	.77	4.69	.63			
I keep every appointment with my transplant doctor		4.67		.63	.40	-
I keep my blood (lab) test appointments		4.71		.63	.40	-
Skin cancer prevention (3 items)	.72	¤	.47			
I use sunscreen when outdoors		3.98 (1.02)	.44	0.20		0.75
I examine (look at carefully) my skin and lips at least once a month		3.89 (1.12)	.62	0.43		0.54
I call my doctor if there is a change or suspicious lesion on my lips or skin		4.25 (.86)	.60	0.41		0.58

Note. $N = 153$. Item mean scores reflect the following response choices: 1 (*strongly disagree*), 2 (*disagree*), 3 (*neutral*), 4 (*agree*), 5 (*strongly agree*). IIC = Inter-Item Correlation. SMC = Squared Multiple Correlation.
[a]Overall Cronbach's alpha for the 16-item scale was .84.

Corrected item-to-total correlation has been used as a criterion for assessing item performance in psychometric testing research, and a range from .30–.90 is recommended (DeVellis, 2012; Netemeyer et al., 2003). The corrected item-to-total correlations for the 16-item KT-SM scale ranged from .38 to .73 (Table 10).

Cronbach's alpha is a diagnostic test to assess internal consistency reliability; a value greater than or equal to .70 is generally accepted (Nunnally & Bernstein, 1994). Cronbach's alpha was .84 for the reduced 16-item scale and ranged from .70 to .83 for the five subscales (see Table 10).

Mean inter-item correlation provides more useful information about internal consistency reliability than Cronbach's alpha, especially when a scale is comprised of very few items (Netemeyer et al., 2003). The mean IIC for the five subscales ranged from 3.8 to 6.3, achieving the investigator's preset goal that mean IIC must be greater than .30 (see Table 10).

In summary, the item-to-total correlation values for each item in the subscales were greater than .38. The IIC for the five subscales ranged from .38 to .63. The Cronbach's alpha values were at .84 overall and had a range of .70 to .83 for the five subscales. Based on these estimates, the investigator concludes that H_2 is supported.

Aim 3: Estimate construct validity of the KT-SM through EFA.

H_3: The EFA results will support that the KT-SM scale is a multidimensional scale with more than one factor extracted, and items within each factor will have factor loading values greater or equal to .40.

The investigator conducted EFA on the 29-item KT-SM scale with a sample of 153 KT recipients; EFA is used to find out the potential dimensions of the construct of

interest (Pett et al., 2003; Polit, 2010; Tabachnick & Fidell, 2012). To determine the factorability of the present data and sampling adequacy, preliminary analyses were conducted as described in this section. First, correlation matrices were inspected to examine whether the values of the correlation coefficients were greater than .25 and less than .90 (Pett et al., 2003; Polit, 2010). One assumption of factor analysis is that variables in a factor should be correlated; if variables are not significantly intercorrelated, factor analysis is not appropriate (Polit, 2010), but if the variables correlate too well ($r \geq .90$), multicollinearity may occur. The correlation matrices presented many coefficients of value 0.25 or above but not exceeding .90 (Table R-1; Appendix R).

The second diagnostic information used to evaluate the factorability in the present dataset was Bartlett's test of sphericity, which tests the null hypothesis that variables in the matrices are orthogonal; failure to reject the null hypothesis indicates that factor analysis is not feasible in this sample (Polit, 2010). The result of Bartlett's test of sphericity was statistically significant ($p = .000$; Table 11). Lastly, the KMO test of sampling adequacy was computed to assess how suitable the sample size was for factor analysis; a KMO value greater than .80 is considered *meritorious* (Beavers et al., 2013, Table 11). The results indicated that the sample size was sufficient, and the data are factorable (Pallant, 2013; Tabachnick & Fidell, 2012).

Table 11

KMO Test and Bartlett's Test

KMO Measure of Sampling Adequacy		.82
Bartlett's Test of Sphericity	Approx. Chi-Square	1786.93
	df	406
	Sig.	.000

Note. $N = 153$.

Initial Factor Analysis

The investigator performed PAF to identify the underlying factor structure of the 29-item KT-SM. The PAF is the most commonly used extraction method in research, with Kaiser's criterion, the eigenvalue-greater-than-1 rule, and Cattell's (1966) scree test the most commonly used factor extraction criteria (Gable & Wolf, 1993; Pallant, 2013). The initial factor extraction yielded 9 factors that accounted for 67.25% of the total variance based on the eigenvalue-greater-than-1 rule (Table 12). The scree plot reveals that 4 factors should be retained (Figure 3), which is consistent with the hypothesis that the KT-SM scale would be composed of four subscales. Experts indicate that Kaiser's eigenvalue-greater-than-one rule is more likely to over-extract factors (Beavers et al., 2013; Pallant, 2013). Therefore, another factor retention criterion was employed: the *5% criterion*, which is determined by *percent of variance extracted*, that is, one factor that accounts for at least 5% of variance will be retained (Pett et al., 2003). As Table 12 depicts, the first 3 factors that met the 5% criterion were 7%, 9.20%, and 7.12%, respectively. The fourth factor was 4.83%, which is close to 5%; therefore, 3 or 4 factors were attainable. Hence, 4 factors were extracted throughout the whole EFA process.

Table 12

Initial Eigenvalues of the 29-Item KT-SM Scale without Varimax Rotation

Factor	Eigenvalues	% of Variance	Cumulative %
1	7.70	26.53	26.53
2	2.58	8.91	35.44
3	2.03	6.98	42.43
4	1.40	4.83	47.25
5	1.36	4.70	51.95

Table continues

6	1.20	4.14	56.09
7	1.13	3.91	60.00
8	1.07	3.71	63.70
9	1.03	3.55	67.25

Note. $N = 153$. Extraction Method: PAF.

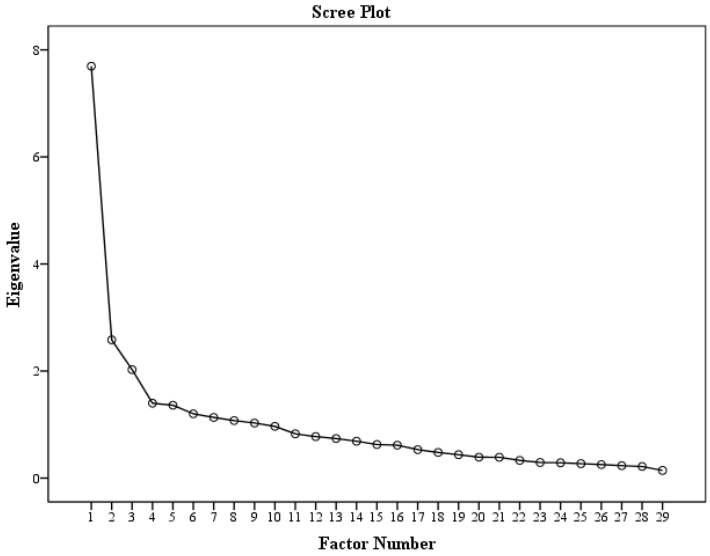

Figure 3. Scree Plot of the 29-Item KT-SM Scale.

To facilitate factor interpretation, varimax rotation was performed after data extraction (Hatcher, 2013; Pallant, 2013; Tabachnick & Fidell, 2012). The goal of factor rotation is to achieve a simple and interpretable factor structure (Netemeyer et al., 2003). After varimax rotation, all variables are uncorrelated, and the items with high loadings are strengthened while the items with low factor loadings are diminished, thus enhancing the interpretability of factors (Polit, 2010; Tabachnick & Fidell, 2012). When a sample size ranges between 150 and 200, a factor loading value of .40 or above is considered statistically significant; therefore, only items with factor loadings ≥ .40 were retained and interpreted (Netemeyer et al., 2003).

In addition, extraction communalities and item correlation matrix were assessed to determine if items needed to be removed. Determinant and reproduced matrices were

examined to see if the final factor solution is adequate (Hatcher, 2013; Pallant, 2013). The item reduction procedure was taken one step at a time, and the factor analytic procedure was conducted after each item deletion occurred until the optimal factor solution was reached, and extraction communality became stable. The following sections describe the steps of item reduction.

Step 1. The EFA results for the 29-item KT-SM Scale showed that 47.25% of the variance was explained by 4 factors. As shown in Table 13, for ease of interpretation, items with loadings < .32 were suppressed. Items that did not load significantly on any factor and had low communality values were considered first for deletion. Communalities are "the amount of variance in each item accounted for by the solution" (Gable & Wolf, 1993, p. 123). Item communality values have been used for additional diagnostic information in determining item deletion in scale development research (Pallant, 2013). An item that has low communality (less than .30; Pallant, 2013) or is not an important contributor to the whole instrument should be eliminated (Pett et al., 2003). Nine items did not have factor loading ≥ .40 and were removed from further analysis. In addition, extraction communalities for most of these items tended to be low. This step of the analyses left 20 items in the KT-SM scale.

Table 13

Rotated Factor Matrix for the 29-Item KT-SM

29-Items of the KT-SM	Factor				
Item	1	2	3	4	h^2
1. I take my antirejection pills as instructed by my transplant doctor		**.77**			.64
2. I call my transplant team if my antirejection pills make me sick		**.77**			.64
3. I do not change the number of antirejection pills		**.35**			.21
4. I use a pill box or other reminder to remember to take my pills					.12
5. I tell my transplant doctor about problems and concerns with my antirejection pills		**.69**	.34		.63
6. If any doctor other than my transplant doctor gives me a new medication, I will call my transplant doctor to make sure it is safe to take		.37	.34		.32
7. I avoid taking nonsteroidal anti-inflammatory drugs (NSAIDS)				0.34	.21
8. I avoid eating sweets, fried foods and other high calorie foods most of the time	**.70**				.55
9. I eat low fat foods like chicken, poultry, lean meats, or low-fat dairy products most of the time.	**.56**				.41
10. I watch how much salt I eat	.38				.33
11. I read food labels most of the time	**.49**				.31
12. I exercise at least 5 times per week	**.57**				.35
13. I limit alcoholic drinks to no more than one drink per day			**.52**		.32
14. I take my blood pressure medication as instructed					.17
15. I look at my feet and ankles to check for swelling as instructed					.22
16. I call my transplant team if I gain more than 3 pounds in one day	.33		**.46**		.42
17. I call my transplant doctor if I pee less than usual		.33	**.51**		.46

Table continues

18. I keep every appointment with my transplant doctor				**.71**	.58
19. I keep my blood test appointments				**.69**	.57
20. I call my transplant doctor when I have signs of an infection			**.80**		.70
21. I take my temperature as instructed by my doctor	**.43**		.32		.38
22. I drink at least eight 8-ounce glasses of water every day	.39				.25
23. I avoid close contact with people who are sick	.33				.27
24. I wash my hands after using the bathroom		**.43**		**.61**	.57
25. I wash my hands before meals			**.42**		.36
26. I use sunscreen when outdoors	**.58**				.38
27. I wear a hat to protect my skin when I am outside	**.42**				.21
28. I examine (look at carefully) my skin and lips at least once a month	**.60**				.49
29. I call my doctor if there is a suspicious lesion on my skin	**.55**			.33	.46
Eigenvalues	7.70	2.58	2.03	1.40	
% of Variance	26.53	8.91	6.98	4.83	

Note. Items with loadings of .40 or greater are in boldface. Items with loadings < .32 were suppressed. H^2 = communality. Extraction method: PAF. Rotation method: varimax with Kaiser normalization.

Step 2. The EFA results for the 20-item KT-SM scale indicate that 57.12% of the total variance was explained by 4 factors. All items loaded strongly with loading size > .40 except item 27, "I wear a hat to protect my skin when I am outside," which had the lowest communality of .23 (Table 14) and was thus deleted, leaving 19 items in the scale.

Table 14

Rotated Factor Matrix for PAF with Varimax Rotation of 20-Item KT-SM.

20-Items of the KT-SM	Factor				
Item	1	2	3	4	h^2
1. I take my antirejection pills as instructed by my transplant doctor		.76			.63

Table continues

2. I call my transplant team if my antirejection pills make me sick		.80			.70
5. I tell my transplant doctor about problems and concerns with my antirejection pills		.64			.58
8. I avoid eating sweets, fried foods and other high calorie foods most of the time	.67				.51
9. I eat low fat foods like chicken, poultry, lean meats, or low-fat dairy products most of the time.	.52				.38
11. I read food labels most of the time	.47				.29
12. I exercise at least 5 times per week	.56				.33
13. I limit alcoholic drinks to no more than one drink per day			.55		.35
16. I call my transplant team if I gain more than 3 pounds in one day			.45		.42
17. I call my transplant doctor if I pee less than usual			.53		.47
18. I keep every appointment with my transplant doctor				.75	.63
19. I keep my blood test appointments				.73	.62
20. I call my transplant doctor when I have signs of an infection			.81		.72
21. I take my temperature as instructed by my doctor	.44				.41
24. I wash my hands after using the bathroom		.42		.60	.55
25. I wash my hands before meals			.41		.34
26. I use sunscreen when outdoors	.59				.38
27. I wear a hat to protect my skin when I am outside	.43				.23
28. I examine (look at carefully) my skin and lips at least once a month	.60				.50
29. I call my doctor if there is a suspicious lesion on my skin	.55				.47
Eigenvalues	6.02	2.26	1.86	1.28	
% of Variance	30.12	11.30	9.32	6.38	

Note. Items with loadings < .38 were suppressed. h^2 = communality. Rotation converged in seven iterations.

Step 3a. The PAF with varimax rotation was performed again on the 19-item scale (Table 15), which accounted for 58.79% of the total variance. Item 25, "I wash my

hands before meals," was eliminated due to a loading size less than .40, resulting in 18 items retained in the KT-SM scale.

Table 15.

Rotated Factor Matrix for PAF with Varimax Rotation of 4-Factor Solution of 19-Item KT-SM

19-Items of the KT-SM	Factor				
Item	1	2	3	4	h^2
1. I take my antirejection pills as instructed by my transplant doctor		.76			.63
2. I call my transplant team if my antirejection pills make me sick		.80			.70
5. I tell my transplant doctor about problems and concerns with my antirejection pills		.64			.59
8. I avoid eating sweets, fried foods and other high calorie foods most of the time	.70				.53
9. I eat low fat foods like chicken, poultry, lean meats, or low-fat dairy products most of the time.	.58				.44
11. I read food labels most of the time	.49				.30
12. I exercise at least 5 times per week	.52				.30
13. I limit alcoholic drinks to no more than one drink per day			.53		.32
16. I call my transplant team if I gain more than 3 pounds in one day			.47		.42
17. I call my transplant doctor if I pee less than usual			.54		.49
18. I keep every appointment with my transplant doctor				.75	.63
19. I keep my blood test appointments				.74	.62
20. I call my transplant doctor when I have signs of an infection			.79		.69
21. I take my temperature as instructed by my doctor	.45				.41
24. I wash my hands after using the bathroom		.43		.60	.56
25. I wash my hands before meals			.39		.34
26. I use sunscreen when outdoors	.55				.34

Table continues

28. I look at carefully my skin and lips at least once a month	.60				.50
29. I call my doctor if there is a suspicious lesion on my skin	.54				.48
Eigenvalues	5.91	2.20	1.79	1.27	
% of Variance	31.12	11.56	9.44	6.67	

Note. Items with loadings < .38 were suppressed. Rotation converged in seven iterations. h^2 = communality.

Step 3b. The rotated factor matrix of the 18 items is presented in Table 16. A total of 60.11% of the variance is explained by the fixed 4-factor solution. While looking at the factor matrix, most of the grouped items were conceptually related, except items 21 and 24. Experts suggest that items should be deleted if they cross- or multi-load strongly or if there is difficulty in interpreting their meanings and results (Pett et al., 2003; Polit, 2010). The characteristics of the items in factor 1 are related to CV risk reduction and skin cancer prevention, except for item 21, "I take my temperature as instructed by my doctor," which did not share anything in common with the other items in factor 1. Furthermore, item 24, "I wash my hands after using the bathroom," loaded on both factors 2 and 3 strongly, yet conceptually it is irrelevant to items in these two factors. Therefore, these two items were removed, resulting in 16 items retained in the KT-SM scale. Whether item 21 and item 24 were deleted together or one-by-one, the results were the same.

Table 16

Rotated Factor Matrix for PAF with Varimax Rotation of 4-Factor Solution of 18-Item KT-SM

18-Items of the KT-SM	Factor				
Item	1	2	3	4	h^2
1. I take my antirejection pills as instructed by my transplant doctor		.76			.62
2. I call my transplant team if my antirejection pills make me sick		.80			.72
5. I tell my transplant doctor about problems and concerns with my antirejection pills		.63		.38	.59
8. I avoid eating sweets, fried foods and other high calorie foods most of the time	.70				.53
9. I eat low fat foods like chicken, poultry, lean meats, or low-fat dairy products most of the time.	.59				.45
11. I read food labels most of the time	.49				.30
12. I exercise at least 5 times per week	.52				.30
13. I limit alcoholic drinks to no more than one drink per day				.50	.29
16. I call my transplant team if I gain more than 3 pounds in one day				.51	.45
17. I call my transplant doctor if I urinate (pee) less than usual				.56	.50
18. I keep every appointment with my transplant doctor			.77		.65
19. I keep my blood (lab) test appointments			.74		.63
20. I call my transplant doctor when I have signs of an infection like fever, flu-like symptoms				.74	.62
21. I take my temperature as instructed by my doctor	.45				.42
24. I wash my hands after using the bathroom		.43	.59		54
26. I use sunscreen when outdoors	.55				.33
28. I examine (look at carefully) my skin and lips at least once a month	.60				.50
29. I call my transplant doctor if there is a change or suspicious lesion on my lips or skin	.54				.49
Eigenvalues	5.58	2.20	1.79	1.26	
% of Variance	31.0	12.2	9.92	6.99	

Note. Items with loadings < .38 were suppressed. Rotation converged in 7 iterations. h^2 = communality.

Finalization of EFA. The EFA results for the remaining 16 items indicated that a total of 61.58% of the total variance is explained by the 4-factor solution. Table 17 displays the factor structure and communality estimates for the 16-item KT-SM. Examining the rotated factor matrix further, one item with cross-loading on two factors was noted. Experts suggest that if an item cross-loads on more than one factor, it should be assigned to the factor that has the higher loading value or be allocated to the factor that is conceptually related (Pett et al., 2003; Polit, 2010). Item 29, "I call my doctor if there is a suspicious lesion on my skin," is conceptually related to the skin cancer items that were grouped in factor 1 and thus was assigned to factor 1. After the allocation, items 16 and 17 were left in factor 4. Likewise, items that related to healthy diet and lifestyle and skin cancer prevention were grouped into one factor. Therefore, the investigator believed a 3- or 5-factor solution might be tenable.

Table 17

Varimax-Rotated Factor Structure: Final Communalities, Eigenvalues, Percentage of Variance, and Reliability for the 16-Item KT-SM Scale

16-Items of the KT-SM	Factor				
Items	1	2	3	4	h^2
1. I take my antirejection pills as instructed by my transplant doctor		.73			.55
2. I call my transplant team if my antirejection pills make me sick		.84			.77
5. I tell my transplant doctor about problems and concerns with my antirejection pills		.68			.64
8. I avoid eating sweets, fried foods and other high calorie foods most of the time	.70				.53

Table continues

9. I eat low fat foods like chicken, poultry, lean meats, or low-fat dairy products most of the time.	.58				.42
10. I read food labels most of the time	.51				.33
11. I exercise at least 5 times per week	.53				.31
12. I limit alcoholic drinks to no more than one drink per day			.53		.31
16. I call my transplant team if I gain more than 3 pounds in one day			.48		.42
17. I call my transplant doctor if I urinate (pee) less than usual			.56		.49
18. I keep every appointment with my transplant doctor				.81	.70
19. I keep my blood (lab) test appointments				.69	.57
20. I call my transplant doctor when I have signs of an infection like fever, flu-like symptoms			.74		.62
26. I use sunscreen when outdoors	.54				.33
28. I examine (look at carefully) my skin and lips at least once a month	.60				.51
29. I call my transplant doctor if there is a change or suspicious lesion on my lips or skin	.53			.38	.49
Eigenvalue	4.92	2.08	1.60	1.25	
% of Variance	30.78	12.98	10.00	7.83	

Note. Items with loadings < .40 were suppressed. h^2 = communality.

However, the EFA results did not support the 3-factor solution, and items 16 and 17 loaded on factor 3 alone while the rest of the items were clustered in two factors, making interpretation of the results even more problematic. The 5-factor solution does successfully separate the three skin cancer-related items to factor 5, and 67.18% of the variance was explained by the solution (Table 18). Item 26 had a slightly low loading value of .39, but it was kept because using sunscreen outdoors is recommended by KT guidelines (Kasiske et al., 2010).

Table 18

Five Factor Structure: Final Communalities, Eigenvalues, Percentage of Variance, and Reliability for the 16-item KT-SM Scale

16-Items of the KT-SM	Factor					
Items	1	2	3	4	5	h^2
1. I take my antirejection pills as instructed by my transplant doctor	.73					.55
2. I call my transplant team if my antirejection pills make me sick	.84					.77
5. I tell my transplant doctor about problems and concerns with my antirejection pills	.68					.64
8. I avoid eating sweets, fried foods and other high calorie foods most of the time		.85				.76
9. I eat low fat foods like chicken, poultry, lean meats, or low-fat dairy products most of the time.		.52				.42
10. I read food labels most of the time		.49				.33
11. I exercise at least 5 times per week		.49				.31
12. I limit alcoholic drinks to no more than one drink per day			.52			.32
16. I call my transplant team if I gain more than 3 pounds in one day			.49			.45
17. I call my transplant doctor if I urinate (pee) less than usual			.58			.52
18. I keep every appointment with my transplant doctor				.89		.86
19. I keep my blood (lab) test appointments				.62		.51
20. I call my transplant doctor when I have signs of an infection like fever, flu-like symptoms			.73			.61
26. I use sunscreen when outdoors		.39			.39	.32
28. I examine (look at carefully) my skin and lips at least once a month					.73	.70
29. I call my transplant doctor if there is a change or suspicious lesion on my lips or skin					.57	.55

Table continues

Eigenvalue	4.92	2.08	1.60	1.25	.90
% of Variance	30.78	12.98	10.00	7.83	5.60
Cronbach's alpha	.83	.70	.72	.77	.72

Note. Items with loadings < .40 were suppressed. h^2 = communality.

To determine if the final 5-factor solution was adequate, the following information was used to evaluate model fit. Determinants of the correlation matrix and reproduced matrices were inspected (see Tables R-2 and R-3, respectively). As shown in the Table R-2 note, the determinant is .002, which is greater than .00001, indicating that no multicollinearity and singularity exist (Leech, Barrett, & Morgan, 2014). The numbers of the reproduced correlations (Table R-3) were close to the original correlations (Table R-2), and values in the residual correlation matrix were small, indicating good model fit (Tabachnick & Fidell, 2012; Yong & Pearce, 2013). As noted in Table R-4, there are nine (7.0%) nonredundant residuals that have absolute values greater than .05; nonredundant residuals less than 50% are preferable (Johnson & Morgan, 2016). Each of these analyses support the adequacy of the 5-factor solution.

Factor naming. Items were grouped per factor as shown in Table 19. Items in four of the five factors were consistent with the hypothesized subscales and used the original names: "medication adherence" for factor 1, "CV risk reduction" for factor 2, "protecting the new kidney" for factor 3, and "skin cancer prevention" for factor 5. Items "I keep every appointment with my transplant doctor" and "I keep my blood (lab) test appointments" in factor 4 were originally developed for the subscale "protecting the new kidney," but the EFA results revealed that these items belonged to factor 4 alone and had higher loading values of .89 and .62, respectively. High loadings indicate that items are unique. The rationale for kidney recipients' keeping doctor and lab appointments is to adjust immunosuppressant doses based on lab results and to monitor graft function and/or

signs of infection (Kasiske et al., 2009). To achieve optimal post-KT results, recipients are expected to make a commitment to be active in their own care by keeping doctor and lab appointments. In addition, ownership of post-transplant care requires effective doctor–patient communications. Hence, factor 4 was given the name, "ownership (partnership) of post-KT care."

Table 19

Reduced 16-Item KT-SM Scale and Its Subscales

Subscale
F1 Medication Adherence (3 items)
I call my transplant team if my antirejection pills make me sick
I take my antirejection pills as instructed by my transplant doctor
I tell my transplant doctor about problems and concerns with my antirejection pills
F2 Cardiovascular disease risk reduction (4 items)
I eat low fat foods like chicken, poultry, lean meats, or low-fat dairy products most of the time
I avoid eating sweets, fried foods and other high calorie foods most of the time
I read food labels most of the time
I exercise at least 5 times per week
F3 Protecting the new kidney (5 items)
I limit alcoholic drinks to no more than one drink per day
I call my transplant doctor if I urinate (pee) less than usual
I call my transplant team if I gain more than 3 pounds in one day
I call my transplant doctor when I have signs of an infection like fever, flu-like symptoms
F4 Ownership of post-transplant self-care (2 items)
I keep every appointment with my transplant doctor
I keep my blood (lab) test appointments
F5 Skin cancer prevention (3 items)
I use sunscreen when outdoors
I examine (look at carefully) my skin and lips at least once a month
I call my transplant doctor if there is a change or suspicious lesion on my lips or skin

Summary. The PAF with varimax rotation identified the underlying factor structure of the 29 items from the KT-SM scale using IBM SPSS version 24. Prior to performing factor analysis, the KMO measure of sampling adequacy and Bartlett's test of sphericity were conducted. The KMO was .82, and Bartlett's test of sphericity was statistically significant, indicating the sample size was adequate and the data are factorable. The EFA results supported that the 16-item KT-SM scale is a multidimensional scale and contains five domains. All 16 items load strongly on 5 factors: medication adherence, CV risk reduction, protecting the new kidney, ownership (partnership) of post-KT care, and skin cancer prevention. Loading sizes ranged from .49–.89, except one, which was .39. The investigator concluded that H^5 and H^6 are supported.

Sequential Multiple Regression

Aim 4: Estimate construct validity of the KT-SM scale guided by the conceptual model by exploring relationships between the KT-SM scale and the SEMCD, the PAM-13, and the KTQ-25.

To determine the strength and direction of each proposed theoretical relationship in the framework, sequential multiple regression was conducted for the variables of self-efficacy, patient activation, KT SM behavior, and HRQoL. Relevant assumptions are examined and described in the following sections.

First, sample size and power needed for multiple regression analysis were computed. Based on the rule of thumb: $N \geq 50 + 8k$ (k represents number of predictor variables; Tabachnick & Fidell, 2012), a total of 153 subjects was considered sufficient to

run the analysis, which achieved a power of .99 and $\alpha = .05$ with an effect size of .34 (Polit, 2010).

The second assumption was that there was no multicollinearity; that is, predictor variables in the model must be uncorrelated. Correlation coefficients of all independent variables (Ivs) were examined and were less than .80 (Cohen, Cohen, West, & Aiken, 2013), indicating that the assumption was met. In addition, the Variance Inflation Factor (VIF) and tolerance for all Ivs ranged from 1.59–1.96 and .51–.73, respectively. The VIF values less than 10 or tolerance greater than .10 indicate no multicollinearity; therefore, the results show that multicollinearity did not occur (Cohen et al., 2003; Tabachnick & Fidell, 2012).

Residual plots for dependent variables were inspected to assess homoscedasticity. The residual plots scattered around the diagonal line from the bottom to the top left, indicating that no heteroscedasticity was present. Multivariate outliers were evaluated by checking the Mahalanobis distance and Cook's distance for all cases. Critical values of chi square (χ^2) were estimated to identify outliers. The critical χ^2 for this sample was 16.92, which was estimated based on $\alpha = .05$ and degree of freedom of 9 (Tabachnick & Fidell, 2012). As presented in Table 20, the maximum value of the Mahalanobis distance is 32.02. This exceeds 16.92, suggesting that outliers exist. Table 21 presents the outlier statistics in the 10 cases with the largest distances. Four cases have values > 16.92 and are considered multivariate outliers. The Cook's distances of these cases were examined to see if they influenced the model results. The maximum value of Cook's distance is .06 (Table 21), which is lower than 1, suggesting no influence (Tabachnick & Fidell, 2012). Therefore, these four cases were retained in the data file.

Table 20

Residuals Statistics

Distance	Min.	Max.	*M*	*SD*	*N*
Mahalanobis Distance	2.71	33.25	9.94	4.22	153.00
Cook's Distance	0.00	0.08	0.01	0.03	153.00

Table 21

Outlier Statistics

	Cases with the Largest Distances	Case Number	Statistic
Mahalanobis Distance	1	147	33.25
	2	63	23.13
	3	28	20.53
	4	73	19.93
	5	1	18.55
	6	153	18.24
	7	91	17.35
	8	83	16,85
	9	50	16.15
	10	75	15.89

Lastly, a visual inspection was done to examine the data distribution of all variables. The SCQ, year of transplant, and year of dialysis were skewed; square root transformation was done on these variables.

H_4: A significant amount of variance in KT SM as measured by the 16-item KT-SM scale and five subscales will be explained by self-efficacy and patient activation, after controlling for demographic and clinical variables.

H_4 was partially supported by results from sequential multiple regressions conducted to investigate the proportion of variance of the KT-SM scale and five domains explained by SEMCD and PAM-13. The six regression equations and findings were examined further per outcome and presented in the section, Screening for categorical variables using MANOVA.

Model building is a crucial step for successful regression analysis (Mendenhall, Sincich, & Boudreau, 2003). An overfitting model (incorporating redundant variables) leads to poor predictions of outcomes and complicates the interpretation process, while an underfitting model omits the effects of important predictor variables and leads to questions about the predictability of included variables (Chatterjee & Simonoff, 2013). For this study, prior to conducting sequential multiple regression analyses, bivariate correlations were examined for predictor variables and criterion variables, and the MANOVA univariate *F* statistic was used to screen categorical variables to be entered into the regression equation. Only variables with significant Pearson *r* values ($p < .05$) or statistically significant *F* test results were entered into the regression equation. Categorical variables including education, marital status, and employment status had unequal cell sizes and thus were combined and recoded into fewer categories and presented as follows. Education was condensed into four levels: high school and under ($n = 21$), some college ($n = 46$), college graduate ($n = 46$), and post graduate ($n = 40$). Marital status had three categories: married ($n = 88$), living with a partner ($n = 16$), and single/divorced ($n = 49$). Employment status was regrouped as retired or receiving supplemental security income ($n = 41$), unemployed ($n = 30$), and employed ($n = 82$). Categorical variables that had statistically significant *F* test results were dummy coded

with numerals per the recommendation from Tabachnick and Fidell (2012) before being entered in the regression model.

Screening for continuous variables using Pearson *r*. As depicted in Table 22, KT recipients' age was significantly positively correlated with KT-SM total score as well as with scores on four of the five domains (r = .21 to .41, $p < .05$; except domain protecting kidney). Years post-transplant was significantly inversely correlated to overall KT-SM (r = -.22, $p < .01$) and to the subscales medication adherence (r = -.19, $p < .05$) and protecting kidney (r = -.25, $p < .01$). Years of pre-transplant dialysis was found to be positively related to medication adherence (r = .20, $p < .05$) but negatively associated with skin cancer prevention (r = -.19, $p < .05$). The predictor variables SEMCD and PAM-13 were positively correlated with the KT-SM total scale score and the five subscales (medication adherence, cardio risk reduction, protecting new kidney, ownership, and skin cancer) with ranges of r = .22 to .50, $p < .01$ and r = .31–.52, $p < .01$, respectively (see Table 23). Therefore, age, square root-transformed years post-transplant, square root-transformed years of pre-transplant dialysis, square root-transformed SCQ score, PAM-13, and SEMCD (measuring self-efficacy) were entered in the regression equation accordingly.

Table 22

Intercorrelations for Overall and Dimensions of KT-SM Scale and Six Independent Variables

KT-SM and domains	Age	Sqrt Years Post-Transplant	Year of Dialysis	Sqrt SCQ	SEMCD	PAM-13
KT-SM total	.35**	-.22**	-.05	-.11	.50**	.52**
Medication adherence	.35**	-.19*	.20*	-.01	.31**	.41**
CV risk reduction	.21*	-.14	-.16	-.09	.38**	.31**
Protecting kidney	.16	-.25**	.03	-.04	.22**	.39**
Ownership	.41**	.01	.01	-.23**	.42**	.36**
Skin cancer	.23**	-.12	-.19*	-.09	.48**	.37**
PAM-13	.16	-.04	.04	-.18*	.53**	-
SEMCD	.24**	.01	-.09	-.34**	-	.53**

Note. $N = 153$. Sqrt = Square root.
*$p < .05$. **$p < .01$. ***$p < .001$.

Table 23

Multivariate and Univariate Analysis of Variance on Discrete Socioeconomic Factors and KT-SM Scale and Five Domains

Factors	Multi-variate *F*	Univariate *F*					
		KT-SM Overall	Meds Adher-ence	CV risk Reduc-tion	Protect-ing Kidney	Owner-ship	Skin Can-cer
Gender[a]	.75	.06	.03	.03	.24	1.07	.72
Marital[b]	2.43**	3.10	1.94	.34	.96	11.48***	2.32
Race[c]	.88	1.68	.05	3.52	.08	.55	2.05
Ethnicity[d]	2.44*	.99	.81	2.33	.15	3.09	.60
Education[e]	1.31	1.49	.82	1.65	1.89	2.33	.74

Table continues

Employment[f]	.98	.64	1.60	.33	.04	1.77	1.16
Tx type[g]	1.79	5.65**	4.60	3.83	3.95	1.30	1.20

Note. Multivariate *F* values were obtained from Pillai's statistics.
[a]Multivariate *df* (5, 146). [b]*df* (10, 294). [c]*df* (5, 147). [d]*df* (5, 145). [e]*df* (15, 441). [f]*df* (10, 294). [g]*df* (5, 146).
$^{*}p < .05$. $^{**}p < .01$. $^{***}p < .001$.

Screening for categorical variables using MANOVA. Separate one-way multivariate analysis of variance (MANOVA) tests were conducted to investigate the effects of gender, marital status, race, ethnicity, education, employment, history of pre-transplant dialysis, and transplant type differences in the overall KT-SM and the five domain scores. Pillai's criterion was used as it is more robust than Wilks' lambda, Hostelling's trace, and Roy's largest root and produces more accurate results when cell sizes are unequal (Hatcher, 2013; Tabachnick & Fidell, 2012).

Variables that had nonsignificant multivariate *F* test results indicated no main effect on the overall dependent variables and were therefore screened for first. Table 24 shows that multivariate *F* tests for gender ($p = .59$), race ($p = .49$), education ($p = .19$), transplant type ($p = .06$), and employment status ($p = .46$) were nonsignificant. However, the *p* value for the main effect of transplant type approached significance, and the univariate *F* test result for the overall KT-SM scale was statistically significant, $F(2, 150) = 5.65$, $p = .004$, indicating that KT recipients who received a living nonrelative kidney had the highest mean score on the overall KT-SM scale compared to non-living donor and living-related donor. Tabachnick and Fidell (2012) suggest that if only a single dependent variable is measured in a study, the univariate *F* effect can still be considered significant. This is not the case for this study, hence, the variables transplant type, gender, race, education, and employment status were first excluded from the sequential multiple regression equations.

Table 24

Variables to be Entered in the Sequential Multiple Regression Equations Displayed per Outcome Variable

Outcome	1st Block	2nd Block
KT-SM Overall	Age, $r = .35^{**}$	PAM-13, $r = .52^{**}$
	years post-transplant sqrt, $r = .22^{**}$	SEMCD, $r = .50^{**}$
Meds adherence	Age, $r = .35^{**}$	PAM-13, $r = .41^{**}$
	Years post-transplant sqrt, $r = -.14^{*}$	SEMCD, $r = .31^{**}$
	Years of dialysis sqrt, $r = -.16^{*}$	
CV risk	Age, $r = .21^{**}$	PAM-13, $r = .31^{**}$
	Years of dialysis sqrt, $r = -.19^{**}$	SEMCD, $r = .38^{**}$
	Years post-transplant sqrt, $r = -.25^{**}$	
Protecting kidney	Years post-transplant sqrt, $r = -.25^{**}$	PAM-13, $r = .39^{**}$
		SEMCD, $r = .22^{**}$
Ownership	Age, $r = .41^{**}$	PAM-13, $r = .36^{**}$
	SCQ-sqrt, $r = -.23^{**}$	SEMCD, $r = .42^{**}$
	Marital status, $F = 11.48$, $\alpha < .000$	
Skin cancer	Age, $r = .23^{**}$	PAM-13, $r = .37^{*}$
	Years of dialysis sqrt, $r = -.19^{**}$	SEMCD, $r = .48^{**}$

$^{*}p < .05$. $^{**}p < .01$. $^{***}p < .001$.

The multivariate F test for marital status [$F(10, 294) = 2.43$, $p = .009$] and ethnicity [$F(5, 145) = 2.44$, $p = .04$] were statistically significant, hence, the univariate F tests for individual dependent variables overall KT-SM scale and the five domains were examined further. The univariate F tests using a Bonferroni adjusted alpha value of .008 ($\alpha = .05/6$ dependent variables) demonstrated a large effect of marital status on ownership of post-KT care, $F(2, 150) = 11.48$, $\eta_p^2 = .13$, $p < .001$. The result of the multivariate F test for ethnicity was statistically significant, but the univariate F tests results were nonsignificant, demonstrating that ethnicity had no effects on overall KT-SM scale or the five domains (see Table 23).

Six pre-test regression models. To test H^4, a series of sequential multiple regressions were conducted to investigate how well the PAM-13 and SEMCD scores explained the variation in the overall KT-SM scale and five domains after controlling for the effects of demographic and clinical factors. Continuous and categorical variables including age, marital status, square root-transformed years of dialysis, square root-transformed comorbidity score, and square root-transformed years post-transplant accordingly were put into the six regression equations to control for their effects on the criterion variables. In the last step, SEMCD and PAM-13 were added to the regression equation (Table 24).

Overall KT-SM. Means, standard deviations, and intercorrelations for the variables to be entered in the regression equation are reported in Table 25.

Table 25

Descriptive Statistics and Intercorrelations for Overall KT-SM Scale and Predictor Variables

Variable	*M*	*SD*	Age	Year Tx sqrt	PAM-13	SEMCD
KT-SM Total	67.02	8.33	.35***	-.22**	.52***	.50***
Age	46.63	12.19		.13	.24**	.16*
Year Tx-sqrt	2.22	1.29	.13		-.04	.01
PAM-13	77.89	15.71	.16	-.04		
SEMCD	7.44	1.80	.24	.01	.53***	

Note. Tx = transplant. Sqrt = Square root-transformed.
* $p < .05$. ** $p < .01$. *** $p < .001$.

Table 26 presents the results for the overall KT-SM scale as an outcome variable. Age and years post-transplant were added in the first block; these explained 20% of the variation in the overall KT-SM scale, $R^2 = .20$, $F(2, 150) = 18.15$, $p < .001$. After step 2, with all predictor variables included, 45% of the variance in the overall KT-SM scale was

explained by the model as a whole, $R^2 = .45$, $F(4, 148) = 30.22$, $p < .001$. The variables SEMCD and PAM-13 explained an additional 26% of the variance in the overall KT-SM scale (R^2 change = .26, sig. F change = .000) after controlling for age and years post-transplant. In examining the final model, all predictor variables made unique significant contributions in explaining the variation in the overall KT-SM scale, with PAM-13 recording a higher beta value ($\beta = .32$, $p < .001$) than SEMCD ($\beta = .28$, $p < .001$), age ($\beta = .27$, $p < .001$), and years post-transplant ($\beta = -.25$, $p < .001$). Positive beta values indicate positive relationships among variables, whereas negative beta values represent negative relationships.

Table 26

Sequential Multiple Regression Analysis for Variables Predicting Overall KT-SM Score

Predictor	R^2	ΔR^2	*B*	*SEB*	β	*t*
Step 1						
Age			.26	.05	.39***	5.23
Sqrt-Year transplant			-1.76	.48	-.27**	-3.67
	.20	.20***				
Step 2						
Age			.18	.04	.27***	4.23
Sqrt-Year transplant			-1.58	.40	-.25***	-4.0
SEMCD			1.28	.34	.28***	3.76
PAM-13			.17	.04	.32***	4.39
	.45	.26***				

*$p < .05$. **$p < .01$. ***$p < .001$.

Correlation coefficients for all variables presented in Table 27 support the direction of the relationships. Correlation coefficients for variables age, PAM-13, and SEMCD range between .35 and .52 ($p < .01$), indicating positive, moderate relationships with the overall

KT-SM scale (Table 27). Years post-transplant was inversely related to overall KT-SM scale (r = -.22, p < .05).

Table 27

Descriptive Statistics and Intercorrelations for Subscale Medication Adherence Scale and Predictor Variables

Variable	*M*	*SD*	M. Adherence	Age	Sqrt-Year transplant	PAM-13
M. Adherence	4.60	.72				
Age	46.63	12.19	.35**			
Sqrt-Year transplant	2.22	1.29	-.19*	.13		
Dialysis-sqrt	1.04	1.01	.20*	.03	-.21**	
PAM-13	77.89	15.71	.41***	.16	-.09	
SEMCD	7.44	1.80	.31***	.24**	.01	.53***

*p < .05. **p < .01. ***p < .001.

Medication adherence. Table 27 provides the means, standard deviations, and bivariate correlations for the variables to be entered in the regression model. To test the ability of SEMCD and PAM-13 to explain the variation in the KT-SM domain medication adherence, age, square root-transformed years post-transplant and square root-transformed years of dialysis were entered in the first step. As presented in Table 28, these three variables explained 20% of the variance in medication adherence, $F(3, 149) = 12.08$, $p < .001$. In the second step, adding SEMCD and PAM-13 in the model accounted for an additional 12% of the variance, $F(2, 147) = 13.00$, $p < .001$. Including all the variables in the final model explained a total of 32% of the variance. However, adding SEMCD (β = .10, p = .24) in the final model did not help predict the medication adherence score. Thus, the investigator concluded that nearly one-third of the variability in medication adherence was predicted by age (β = .30, p < .001), PAM-13

(β = .29, $p < .001$), years post-transplant (β = -.19, $p < .01$), and years of pre-transplant dialysis (β = .15, $p < .05$). The variables age, years of pre-transplant dialysis, and PAM-13 are positively correlated to medication adherence (r =.20 to .41, $p < .01$), whereas years post-transplant (r =.19, $p < .01$) is inversely correlated to medication adherence.

Table 28

Sequential Multiple Regression Analysis Summary for Variables Predicting Subscale Medication Adherence Score (N = 153)

Variable	R^2	ΔR^2	*B*	SE*B*	β	*t*
Step 1						
Age			.02	.00	.37***	4.96
Sqrt-Year transplant			-.12	.04	-.21**	-2.74
Sqrt-Year dialysis			.01	.06	.15	1.94
	.20	.23**				
Step 2						
Age			.02	.00	.30***	4.71
Sqrt-Year transplant			-.10	.04	-.19**	-2.64
Sqrt-Year dialysis			.11	.05	.15*	2.10
SEMCD			.04	.03	.10	1.19
PAM-13			.01	.00	.29***	3.62
	.32	.12***				

*$p < .05$. **$p < .01$. ***$p < .001$.

CV risk reduction. Sequential multiple regression was conducted again to investigate the ability of SEMCD and PAM-13 to explain the variation of the KT-SM domain CV risk reduction. Descriptive statistics and bivariate correlations for testing variables are presented in Table 29.

Table 29

Descriptive Statistics and Intercorrelations for the KT-SM Subscale CV Risk Reduction

Variable	*M*	*SD*	CV risk reduction	Age	PAM-13
CV risk reduction	3.56	.82			
Age	46.63	12.19	.21**		
Years post KT	6.19	6.59	-.14*		
Year of pre-dialysis	2.10	3.11	-.16*		
PAM-13	77.89	15.71	.31***	.16	
SEMCD	7.44	1.80	.38***	.24**	.53***

*$p < .05$. **$p < .01$. ***$p < .001$.

In the first step, adding the variables age, years post-KT, and years of pre-transplant dialysis explained 11.1% of the variance in the domain, $F(3, 149) = 6.19$, $p < .001$ (see Table 30). After step 2, with the variables PAM-13 and SEMCD included in the equation, the total variance explained as a whole was 23%, $F(2, 147) = 11.32$, $p < .001$. The introduction of PAM-13 and SEMCD accounted for an additional 12% (sig. *F* change = .000) of the variance in explaining CV risk reduction after controlling for age, years post-KT, and years of pre-transplant dialysis. The final model incorporated the variables age ($\beta = .16$, $p < .05$), years post-KT ($\beta = -.19$, $p < .05$), years of pre-transplant dialysis ($\beta = -.18$, $p < .05$), and SEMCD ($\beta = .25$, $p < .01$). Years post-KT and years of pre-transplant dialysis were negative predictors of CV risk behavior, which means that longer years post-KT and longer duration of pre-transplant dialysis were correlated with high likelihood not to practice CV risk reduction behaviors. The results of bivariate correlational analysis displayed in Table 29 show a positive association between PAM-13 and CV risk reduction, yet the PAM-13 did not reach statistical significance in predicting CV risk reduction scores. However, SEMCD made a statistically significant contribution to the model in predicting CV risk reduction score.

Table 30

Sequential Multiple Regression Analysis Summary for Variables Predicting Subscale CV Risk Reduction Score

Variable	R^2	ΔR^2	*B*	SE*B*	β	*t*
Step 1						
Age			.02	.01	.24**	3.09
Years post-KT			-.13	.05	-.21**	-2.65
Year of pre-dialysis			-.17	.06	-.21*	-2.61
	.11	.11***				
Step 2						
Age			.01	.01	.16*	2.05
Years post-KT			-.12	.05	-.19*	-2.55
Year of pre-dialysis			-.15	.06	-.18*	-2.45
SEMCD			.13	.04	.28**	3.15
PAM-13			.01	.01	.14	1.59
	.23	.12***				

*$p < .05$. **$p < .01$. ***$p < .001$.

Protecting kidney. Correlation coefficients of the predictor variables and outcome variable range between $r = -.25$ and .39, $p < .01$ (Table 31). Adding square root-transformed years post-transplant in the first block explained 6.3% of the variance in protecting kidney, $F(1, 151) = 10.23$, $p < .01$.

Table 31

Descriptive Statistics and Intercorrelations for KT-SM Subscale Protecting Kidney and Predictor Variables

Variable	*M*	*SD*	Protecting kidney	Year Tx sqrt	PAM-13
Protecting kidney	4.36	.69			
Sqrt-Year transplant	2.22	1.29	-.25***		
PAM-13	77.89	15.71	.39**	-.09	
SEMCD	7.44	1.80	.22***	.01	.53***

*$p < .0.5$ **$p < .01$. ***$p < .001$.

After step 2, with the variables PAM-13 and SEMCD included, 20.6% of the variance in protecting kidney was explained by the model as a whole (Table 32). Adding PAM-13 and SEMCD explained an additional 13.36% of variance (sig. *F* change =.000) after controlling for the effect of years post-transplant. In the final model, two of the three variables have statistically significant β-values: PAM-13 ($\beta = .36$, $p < .001$) and years post-transplant ($\beta = -.24$, $p < .01$). PAM-13 is the stronger positive predictor in predicting the protecting kidney score, whereas years post-transplant may be used to predict the inverse outcome. The more years post-transplant, the lower the score on protecting kidney is expected to be. In other words, the longer a person has had a KT, the less likely he or she is to perform kidney-protecting behaviors.

Table 32

Sequential Multiple Regression Analysis Summary for Variables Predicting Subscale Protecting Kidney Score (N = 153)

Predictor	R^2	ΔR^2	*B*	SE*B*	β	*t*
Step 1						
Sqrt-Year transplant			-.14	.04	-.28**	-3.20
	.06	.06**				
Step 2						
Sqrt-Year transplant			-.13	.04	-.24**	-3.24
SEMCD			.00	.03	.03	.35
PAM-13			.02	.00	.36***	4.18
	.21	.14***				

*$p < .05$. **$p < .01$. ***$p < .001$.

Ownership. Marital status was dummy coded into three categories: married, living with a partner, and single/divorced, with married as the reference group. In step 1, living with a partner, single/divorced, age, and square root-transformed SCQ were entered in the first block; these explained 29.4% of the variance in ownership (see Table 33).

Table 33

Descriptive Statistics and Intercorrelations for KT-SM Subscale Ownership and Predictor Variables (N = 153)

Variable	*M*	*SD*	Ownership
Ownership	4.69	.63	-
Married	4.83	.35	.27***
Living with a partner	4.91	.27	.12
Single/divorced	4.36	.91	-.36***
Age	46.63	12.19	.41***

Table continues

Sqrt-SCQ	2.00	.98	-.23**
PAM-13	77.89	15.71	.42***
SEMCD	7.44	1.80	.36***

*$p < .05$. **$p < .01$. ***$p < .001$.

After adding SEMCD and PAM-13 in the second block, 37.2% of the total variance was explained by the model as a whole, $F(6, 146) = 14.40$, $p < .001$. PAM-13 and SEMCD explained an additional 8% of the variance in ownership, after controlling for marital status, age, and square root-transformed SCQ, $\Delta R^2 = .08$, F change $(2, 146) = 9.05$, $p < .001$. In the final adjusted model, age, single/divorced, and SEMCD were statistically significant, with age ($\beta = .29$, $p < .001$) recording a higher beta weight value than single/divorced ($\beta = -.24$, $p < .001$), and SEMCD ($\beta = .20$, $p < .05$). (See Table 34.)

Table 34

Sequential Multiple Regression Analysis Summary for Variables Predicting Subscale Ownership Score (N = 153)

Predictor	R^2	ΔR^2	*B*	SE*B*	β	*t*
Step 1						
Living with a partner			.13	.15	.06	.86
single/divorced			-.33	.10	-.25**	-.33
Age			.02	.00	.36***	4.99
Sqrt-SCQ			-.14	.05	-.22**	-3.08
	.29	.29**				
Step 2						
Living with a partner			.08	.14	.04	.56
single/divorced			-.32	.09	-.24**	-3.37
Age			.02	.00	.29***	4.04
Sqrt-SCQ			-.08	.05	-.12	-1.72
SEMCD			.07	.03	.20*	2.42
PAM-13			.01	.00	.15	1.88
	.37	.08***				

*$p < .05$. **$p < .01$. ***$p < .001$.

Skin cancer prevention. Table 35 presents the descriptive statistics and bivariate correlations for variables to be tested in the regression model.

Table 35

Descriptive Statistics and Intercorrelations for KT-SM Subscale Skin Cancer Prevention and Predictor Variables

Variable	*M*	*SD*	Skin cancer I
Skin cancer	4.04	.80	-
Age	46.63	12.19	.23**
Sqrt- Year dialysis	1.04	1.01	-.19**
SEMCD	7.44	1.80	.48***
PAM-13	77.88	15.71	.37***

*$p < .05$. **$p < .01$. ***$p < .001$.

As shown in Table 36, in Step 1, age and square root-transformed years of pre-transplant dialysis were entered in the first block, explaining 9% of the variance in skin cancer. After entering SEMCD and PAM-13 in the second block, 29% of the total variance was explained by the model as a whole, $F(4, 148) = 14.96$, $p < .001$. PAM-13 and SEMCD explained an additional 20% of the variance in skin cancer, after controlling for age and square root-transformed years of pre-transplant dialysis, $\Delta R^2 = .20$, F change $(2, 148) = 20.48$, $p < .001$. In the final model, years of pre-transplant dialysis, PAM-13, and SEMCD were statistically significant, with SEMCD ($\beta = .34$, $p < .001$) recording a higher beta value than PAM-13 ($\beta = .18$, $p < .05$) and years of pre-transplant dialysis ($\beta = -.17$, $p < .05$). Years of pre-transplant dialysis has a negative value, indicating a negative relationship with the domain skin cancer; this finding was consistent with the result of the bivariate intercorrelations of skin cancer prevention and years of pre-transplant dialysis presented in Table 35.

Table 36

Sequential Multiple Regression Analysis Summary for Variables Predicting Subscale Skin Cancer Prevention Score (N = 153)

Predictor	R^2	ΔR^2	*B*	SE*B*	β	*t*
Step 1						
Age			.02	.01	.23**	2.98
Sqrt-Year dialysis			-.16	.06	-.20*	-2.54
	.09**	.09**				
Step 2						
Age			.01	.01	.12	1.73
Sqrt-Year dialysis			-.14	.06	-.17*	-2.45
SEMCD			.15	.04	.34***	4.05
PAM-13			.01	.00	.18*	2.13
	.29***	.20***				

Note. $\Delta R^2 = R^2$ change.
*$p < .05$. **$p < .01$. ***$p < .001$

In summary, intercorrelations for the five domains ranged from $r = .19$ to .55, $p < .05$. Pearson correlation coefficients for the KT-SM overall score and five domains were moderate to strong, $r = .51$ to .76, $p < .01$. The six regression models composed of socioeconomic variables, clinical factors, PAM-13, and SEMCD explained significant amounts of variation (see Table 37) in the overall KT-SM (45%) and the domains medication adherence (32%), CV risk reduction (18%), protecting kidney (21%), ownership (37%), and skin cancer prevention (29%). Based on further examination of the final models, the PAM-13 was not statistically significant in predicting scores for the domains CV risk reduction and ownership, and SEMCD was not a significant predictor of protecting kidney behavior. Therefore, H^5 was partially met.

Table 37

Six Equation Models for Predicting Scores on Overall KT-SM and 5 Domains

Outcome	Predictor	% of variance explained
KT-SM total	β_0 (constant) + β_1 (age) + β_2 (years post transplant) + β_3 (PAM-13) + β4 (SEMCD)	45%
M. adherence	β_0 + β_1 (age) + β_2 (years post transplant) + β_3 (PAM-13)	32%
CV risk	β_0 + β_1 (age) + β_2 (years post transplant) + β_3 (years of pre-transplant dialysis) + β_4 (SEMCD)	23%
Protecting kidney	β_0 + β_1 (years post transplant) + β_2 (PAM-13)	21%
Ownership	β_0 + β_1 (single/divorced) + β_2 (age) + β_3 (SEMCD)	37%
Skin cancer	β_0 + β_1 (years of pre-transplant dialysis) + β_2 (PAM-13) + β_3 (SEMCD)	29%

H_5: Controlling for demographic and clinical variables, a significant amount of variance in HRQoL will be explained by self-efficacy, patient activation, and KT-SM behavior.

H_5 was partially supported. The six regression models composed of characteristics, clinical factors, and SEMCD explained significant amounts of variation in the overall KTQ-25 (47%) and the subscales physical symptoms (42%), fatigue (43%), uncertainty/fear (19%), appearance (26%), and emotion (33%). The PAM-13 and KT-SM scores were not statistically significant in predicting scores for the overall KTQ-25 and four of the five subscales, except KT-SM domain CV risk reduction.

Prior to conducting sequential multiple regression, categorical and continuous variables were screened using MANOVA *F* statistics and Pearson's product-moment correlation, respectively. Categorical variables that had insignificant *F* test values and continuous variables that were not statistically significantly correlated to criterion variables were excluded from the regression equation.

Table 38 presents results of the one-way MANOVA. Using Pillai's trace (Λ) criterion, there were significant differences in the combined dependent variables of the KTQ-25 overall and the five subscales for gender, $F(5, 146) = 3.33$, $p = .007$; $\Lambda = .10$; education, $F(15, 441) = 2.66$, $p < .001$; $\Lambda = .10$; and employment status, $F(10, 294) = 2.18$, $p < .05$; $\Lambda = .14$. Given the statistically significant results of the multivariate tests, univariate tests of between-subject effects were conducted on gender, education, and employment differences separately.

Table 38

Multivariate and Univariate Analysis of Variance for KTQ-25 and 5 Subscales

	Multi-variate *F*	Univariate *F*					
		KTQ Overall	Physi-cal	Fatigue	Uncer-tainty	Appear-ance	Emotion
Gender[a]	3.33**	4.82**	4.82	10.5**	3.70	11.31**	2.65
Marital[b]	1.43	.64	.35	1.64	2.99	.14	.80
Race[c]	1.60	1.32	1.42	.17	4.00	1.19	2.28
Ethnicity[d]	.58	.55	.03	.23	2.14	.05	1.18
Education[e]	2.66**	3.16	6.12**	1.62	2.91	.34	2.66
Employ-ment[f]	2.18*	4.85	4.91	2.67	4.13	1.27	3.69
Tx type[h]	.28	.21	.12	.32	.29	.50	.04

Note. Multivariate *F* values were obtained from Pillai's statistics.
[a]*df* (5, 146). [b]*df* (10, 294). [c]*df* (5, 147). [d]*df* (5, 145). [e]*df* (15, 441). [f]*df* (10, 294).
[g]*df* (5, 146). [h]*df* (10, 294).
* $p < .05$. ** $p < .01$.*** $p < .001$.

Using a Bonferroni corrected alpha value of .008, univariate *F* tests results were further examined on gender, education, and employment status. The results presented in Table 39 show that there were significant gender differences on the overall KTQ-25,

F = (1, 150) = 9.39, p = .003; fatigue F = (1, 150) = 10.5, p = .001; and appearance, F = (1, 150) = 11.31, p = .001.

Table 39

Mean- Post Hoc Tests

Groups	KTQ-25 Total	Physical Symptoms	Fatigue	Uncertainty	Appearance	Emotion
Gender	*M* (*SD*)	*M* (*SD*)	*M* (*SD*)	*M* (*SD*)	*M* (*SD*)	*M* (*SD*)
Female	4.73 (1.15)	-	4.29 (1.55)	-	5.52 (1.20)	-
Male	5.29 (.95)	-	5.12 (1.43)	-	6.14 (.89)	-
Education						
High school and under		4.26 (1.89)***				
Some college		4.34 (1.59)***				
College & graduate		4.90 (1.37)				
Post graduate		5.64 (1.53)***				

Note. Independent variables had no significant effects on KTQ and five subscales are left blanks.
*p < .05. **p < .01. ***p < .001

Females reported lower scores than men on the overall KTQ-25 and the subscales fatigue and appearance (see Table 40); a higher score indicates perceived less or no distress and a better quality of life. Univariate F test results indicated that education level had an effect on the KTQ-25 subscale physical symptoms, F = (3, 149) = 6.12, p = .001. Employment status had effects on overall KTQ-25, F = (3, 149) = 5.21, p = .002; physical symptoms, F = (3, 149) = 5.56, p = .001; and uncertainty/fear, F = (3, 149) = 4.92, p = .003. Post-hoc multiple comparisons using Tamhane's T2 test revealed that mean scores for the employed group were statistically significantly higher than for the unemployed group on

overall KTQ-25 (M = 5.24, SD = .96), the physical symptoms subscale (M = 5.32, SD = 1.44), and the uncertainty subscale (M = 5.0, SD = 1.32).

Based on the MANOVA test results, the categorical variables gender and education that had statistically significant F test results were entered into the first block of the sequential regression model.

Intercorrelations. Table 40 presents the intercorrelations for overall and each dimension of the KTQ-25 with four clinical variables, SEMCD, and PAM-13. Age was significantly positively related to overall KTQ-25 and three of the five subscales (except physical symptoms and fatigue), with Pearson's r ranging between .23–.28; $p < .01$. Years post-transplant was not statistically significantly correlated with overall KTQ-25 or its five subscales. Years of dialysis was only significantly inversely associated with emotion (r = -.16, $p < .05$). Comorbidity scores (square root-transformed SCQ) were negatively related to scores on the overall KTQ-25 and five subscales (r = -.17 to -.40, $p < .05$). SEMCD was positively correlated with overall KTQ and five subscales (r = .35 to .61), while PAM-13 was only positively related to KTQ overall and the subscales physical symptoms and emotion (r = .20 to .24).

Table 40

Intercorrelations for Overall and Dimensions of KTQ-25 and Six Predictor Variables

KTQ-25 and subscales	Age	Sqrt years post transplant	Sqrt year of dialysis	Sqrt SCQ	SEMCD	PAM-13
KTQ-25 overall	.24**	.04	-.15	-.40**	.61**	.22**
Physical symptom	.12	.11	-.15	-.36**	.52**	.20*
Fatigue	.15	-.07	-.09	-.44**	.54**	.16
Uncertainty/fear	.23**	.05	-.15	-.17*	.40**	.13

Table continues

Appearance	.24**	.04	.04	-.28**	.35**	.24**
Emotion	.28**	.01	-.16*	-.25**	.50**	.16

Note. $N = 153$. Sqrt = Square root.
*$p < .05$. **$p < .01$. ***$p < .001$.

Intercorrelations for overall and each dimension of the KT-SM and KTQ-25 are displayed in Table 41. KT-SM total was positively correlated with KTQ total and four of the five subscales ($r = .23$ to 32, $p < .01$), except subscale uncertainty/fear. Medication adherence was positively related to KTQ total and the subscales physical symptoms and appearance with Pearson's *r* ranging between .16 and .24. CV risk reduction was positively related to all subscales except uncertainty/fear, and *r* ranged from .25 to .34. Protecting kidney was not statistically significantly related to overall KTQ-25 and its subscales. Ownership was correlated with overall KTQ-25 and five subscales, with Pearson's *r* ranging from .17 to .31. Skin cancer was positively related to KTQ-25 total, physical symptoms, fatigue, and emotion subscales ($r = .21$ to 33).

Table 41

Intercorrelations for Overall and Dimensions of KTQ-25 and KT-SM Scale

KTQ-25 and subscales	KT-SM Total	Medication adherence	CV risk reduction	Protecting kidney	Ownership	Skin cancer
KTQ-25 total	.32**	.20*	.30**	.07	.31**	.27**
Physical symptom	.30**	.16*	.25**	.07	.29**	.33**
Fatigue	.27**	.16	.26**	.07	.29*	.21*
Uncertainty/fear	.10	.07	.11	-.09	.17*	.16
Appearance	.23**	.24**	.20*	.07	.23*	.11
Emotion	.32**	.16	34**	.16	.20*	.23*

*$p < .05$. **$p < .01$. ***$p < .001$.

In summary, the variables entered in the six sequential multiple regression models for testing H^6 are summarized and displayed in Table 42.

Table 42

Variables to be Entered in the Sequential Multiple Regression Equations Displayed per Outcome KTQ-25 and Five Subscales

Outcome	1st Block	2nd Block	3rd Block
KTQ total	Gender, $F = 4.82$, $\alpha = .003$ Age, $r = .40^{**}$ SCQ, $r = -.15^{*}$	SEMCD, $r = .60^{**}$ PAM-13, $r = .22^{**}$	KT-SM Total, $r = .32^{**}$
KTQ-1 physical	Education, $F = 3.16$, $\alpha = .001$ SCQ, $r = .15^{*}$ Year dialysis, $r = .20^{*}$	SEMCD, $r = .52^{**}$ PAM-13, $r = .20^{*}$	Meds adherence, $r = .16^{*}$ CV risk, $r = .25^{**}$ Ownership, $r = .29^{**}$ Skin cancer, $r = .33^{**}$
KTQ-2 Fatigue	Gender, $F = 10.5$, $\alpha = .001$ SCQ, $r = -.44^{**}$	SEMCD, $r = .54^{**}$	CV risk, $r = .26^{**}$ Ownership, $r = .29^{**}$ Skin cancer, $r = .21^{*}$
KTQ-3 Uncertainty	Age, $r = .23^{**}$ SCQ, $r = -.17^{*}$	SEMCD, $r = .40^{**}$	Ownership, $r = .17^{*}$
KTQ-4 Appearance	Gender, $F = 11.31$, $\alpha = .001$ Age, $r = .24^{**}$ SCQ, $r = -.28^{**}$	SEMCD, $r = .35^{**}$ PAM-13, $r = .24^{**}$	Meds adherence, $r = .24^{**}$ CV risk, $r = .20^{*}$ Ownership, $r = .23^{**}$
KTQ-5 Emotion	Age, $r = .28^{**}$ Year of dialysis, $r = -.16^{*}$ SCQ, $r = -.25^{**}$	SEMCD, $r = .50^{**}$	CV risk, $r = -.34^{**}$ Ownership, $r = -.20^{**}$ Skin cancer, $r = -.23^{**}$

$^{*}p < .05$. $^{**}p < .01$. $^{***}p < .001$.

Overall KTQ-25 scale as outcome. Age, gender, and square root-transformed SCQ were introduced in the first block to control for the effects. As presented in Table 43, introducing these three variables explained 26% of the variance in the KTQ-25 total score, $R^2 = .26$, $F(3, 147) = 17.02$, $p < .001$. PAM-13 and SEMCD scores were then entered in the second block; adding these explained an additional 21% of the variance in

the KTQ-25 total score, R^2 change (ΔR^2) = .21, $F(5, 145) = 25.92$, sig. F change = .000. KT-SM total was added in the last block, and 47% of the variability in the KTQ-25 total score was explained by the model as a whole, $R^2 = .47$, $F(6, 144) = 21.65$, $p = .000$. However, adding the total KT-SM scale in Model 3 had no explanatory power in the proportion of the variance explained in the overall KTQ-25 scale (R^2 change = .00, sig. F change = .48), after controlling for age, gender, SCQ, PAM-13, and SEMCD.

Table 43

Sequential Multiple Regression Analysis Summary for Variables Predicting Overall KTQ

Predictor	R^2	ΔR^2	*B*	SE	β	*t*
Step 1						
Gender			.48	.17	.21	2.89**
Age			.02	.01	.23	3.27**
Sqrt-SCQ			-.44	.08	-.39	-5.42**
	.26**	.26**				
Step 2						
Gender			.46	.14	.20	3.26**
Age			.01	.01	.11	1.80
Sqrt-SCQ			-.24	.07	-.21	-3.24**
PAM-13			-.01	.01	-.09	-1.18
SEMCD			.34	.05	.55	7.12**
	.47**	.21**				
Step 3						
Gender			.46	.14	.20	3.27**
Age			.01	.01	.10	1.53
Sqrt-SCQ			-.24	.07	-.21	-3.28**
PAM-13			-.01	.01	-.11	-1.39
SEMCD			.33	.05	.54	6.67**
KT-SM Total			.01	.01	.06	.80
	.47	.00				

*$p < .05$. **$p < .01$. ***$p < .001$.

When the six independent variables were included in the final model, only SEMCD (β = .54, $p < .001$), square root-transformed SCQ (β = -.21, $p < .001$), and gender (β = .20, $p < .001$) made significant contributions in predicting overall KTQ-25

score. The SEMCD is the most important predictor, explaining 24.5% of the variation in the KTQ-25 total score. Square root-transformed SCQ had negative beta values, indicating an inverse relationship between scores on comorbid conditions and post KT quality of life (r = -.40, p < .000).

KTQ-25 subscale physical symptoms. Education was dummy coded into four levels and entered in the first step with the variables square root-transformed years of dialysis and square root-transformed SCQ (Table 44); these explained 22% of the variance in the physical symptoms subscale, F change (5, 146) = 8.27, p < .001. Introducing PAM-13 and SEMCD in step 2 resulted in an additional 15% of the variance explained in the physical symptoms subscale, F change (7, 144) = 13.20, p < .001. In the last step, four of five domains of the KT-SM scale (medication adherence, CV risk reduction, ownership, and skin cancer prevention) were added in the equation to determine their ability to predict KTQ-25 subscale physical symptoms, and nearly 42% of the variability in the KTQ physical symptoms subscale was explained by the model as a whole, F(11, 140) = 9.03, p< .001. Nevertheless, the inclusion of these four KT-SM domains resulted in no improvement in R^2 change, ΔR^2 = .02, sig. F change = .28.

In examining the regression coefficients for each predictor variable in the final model, beta weights for college/graduate degree (p = .15), years of pre-transplant dialysis (p = .70), PAM-13 (p = .30), and the KT-SM domains medication adherence (p = .29), CV risk reduction (p = .76), ownership (p = .50), and skin cancer prevention (p = .22) were not statistically different from zero. The variables SEMCD (β = .37, p < .001), received some college education (β = -.34, p < .001), SCQ score (β = -.21, p < .05), and received high school education or less (β = -.19, p < .005) significantly contributed to

predicting KTQ-25 physical symptoms. Participants who perceived a higher level of self-efficacy reported fewer physical symptoms and experienced less distress from the physical symptoms; a higher score on the KTQ-25 physical symptoms subscale indicated no symptoms or distress at all. The SCQ score, received some college education, and received high school or less education were negatively related to physical symptoms.

Table 44

Sequential Multiple Regression Analysis Summary for Variables Predicting Subscale: Physical Symptoms

Predictor	R^2	ΔR^2	*B*	SE*B*	β	*t*
Step 1						
High school/under			-1.14	.40	-.24**	-2.83
Some college			-1.16	.32	-.33***	-3.59
College graduate			-.65	.32	-.18*	-2.04
Sqrt-year dialysis			-.10	.12	-.06	-.85
Sqrt-SCQ			-.54	.12	-.32***	-4.41
	.22	.22**				
Step 2						
High school/under			-.90	.36	-.19*	-2.49
Some college			-1.08	.29	-.31**	-3.75
College graduate			-.43	.29	-.12	-1.50
Sqrt-year dialysis			-.06	.11	-.04	-.53
Sqrt-SCQ			-.30	.12	-.18*	-2.59
PAM-13			.00	.01	-.04	-.50
SEMCD			.42	.08	.47**	5.59
	.39	.17**				
Step 3						
High school/under			-.94	.36	-.20**	-2.58
Some college			-1.16	.29	-.33***	-4.02
College graduate			-.41	.29	-.11	-1.41
Sqrt-year dialysis			-.04	.11	-.03	-.38
Sqrt-SCQ			-.32	.12	-.19**	-2.75
PAM-13			-.01	.01	-.12	-1.38
SEMCD			.35	.08	.39***	4.39

Table continues

M. adherence			.18	.17	.08	1.06
CV risk reduction			.04	.16	.02	.27
Ownership			.19	.20	.07	.94
Skin cancer			.23	.18	.11	1.27
	.42	.02				

Note. $N = 152$.
$^{*}p < .05$. $^{**}p < .01$. $^{***}p < .001$.

KTQ-25 subscale fatigue. The variables gender and square root-transformed SCQ were entered in the first block and accounted for 25% of the variance in the subscale fatigue, $F(2, 148) = 24.48$, $p < .001$ (see Table 45). The SEMCD was then introduced in the second block, explaining an additional 17% of the variance in the subscale fatigue, after controlling for gender and square root-transformed SCQ, $F(3, 147) = 35.55$, $p < .001$. In the last step, the three KT-SM domains, CV risk reduction, ownership, and skin cancer prevention were added to the equation; 43% of the total variance was explained by the model as a whole, after controlling for the other variables previously entered, $F(6, 144) = 18.07$, $p < .001$. Nevertheless, adding the three KT-SM variables resulted in no improvement in the R^2 increment, $\Delta R^2 = .01$, sig. F change = .52. As shown in the final model presented in Table 45, SEMCD ($\beta = .43$, $p < .001$) was the most important contributor in predicting fatigue score, suggesting that KT recipients who perceived higher self-efficacy experienced less fatigue. Square root-transformed SCQ ($\beta = -.27$, $p < .001$) and gender ($\beta = .21$, $p < .01$) had significant negative coefficients, indicating that kidney recipients with more comorbidities or who were female were prone to experience more fatigue.

Table 45

Sequential Multiple Regression Analysis Summary for Variables Predicting Subscale: Fatigue

Predictor	R^2	ΔR^2	*B*	SE*B*	β	*t*
Step 1						
Gender			.75	.23	.23**	3.23
Sqrt-SCQ			-.67	.11	-.43**	-5.95
	.25	.25**				
Step 2						
Gender			.73	.20	.22***	3.56
Sqrt-SCQ			-.43	.11	-.27***	-4.08
SEMCD			.38	.06	.44**	6.60
	.42	.17**				
Step 3						
Gender			.69	.21	.21**	3.35
Sqrt-SCQ			-.42	.11	-.27***	-3.91
SEMCD			.37	.07	.43**	5.41
CV risk reduction			.20	.15	.10	1.36
Ownership			.12	.18	.05	.64
Skin cancer			-.18	.16	-.09	-1.10
	.43	.01				

Note. $n = 151$.
$^{*}p < .05$. $^{**}p < .01$. $^{***}p < .001$.

KTQ-25 subscale uncertainty/fear. As shown in Table 46, age and square root-transformed SCQ were entered in the first block and accounted for 8% of the variance in the KTQ subscale uncertainty/fear, $F(2, 149) = 6.63$, $p < .01$. Introducing the variable SEMCD in the second step explained an additional 10% of variance in the subscale uncertainty/fear, $F(3, 148) = 11.06$, $p < .001$ after other variables were controlled. The inclusion of ownership in the final model explained a total of 19% of variance by the model as a whole, $F(4, 147) = 8.42$, $p < .001$. Nonetheless, including ownership did not improve R^2 change, $\Delta R^2 = .00$, sig. *F* change = .45. In the final model, only age and SEMCD were important predictors of uncertainty/fear, and the SEMCD

(β = .37, $p < .001$) had higher beta weight than age (β = .17, $p < .05$). Knowing the kidney recipient's age and perception of self-efficacy in taking care of the new kidney only explained a small proportion of the variance in uncertainty/fear.

Table 46

Sequential Multiple Regression Analysis Summary for Variables Predicting Subscale: Uncertainty/Fear

Predictor	R^2	ΔR^2	*B*	SE *B*	β	*t*
Step 1						
Age			.03	.01	.23**	2.96
Sqrt-SCQ			-.24	.11	-.18*	-2.24
	.08	.08**				
Step 2						
Age			.02	.01	.14	1.87
Sqrt-SCQ			-.07	.11	-.05	-0.64
SEMCD			.27	.06	.35***	4.29
	.18	.10**				
Step 3						
Age			.02	.01	.17*	2.01
Sqrt-SCQ			-.08	.11	-.06	-.75
SEMCD			.28	.06	.37***	4.32
Ownership			-.14	.19	-.07	-.76
	.19	.00				

Note. $n = 151$.
*$p < .05$. **$p < .01$. ***$p < .001$.

KTQ-25 subscale appearance. The first block was composed of gender, age, and square root-transformed SCQ; it accounted for 19% of the variance in appearance, $F(3, 147) = 11.34$, $p < .001$ (Table 47). SEMCD was then added in the second block, but it explained only an additional 6% of the variance in appearance, $F(3, 147) = 11.34$, $p < .001$, after controlling for gender, age, and square root-transformed SCQ. The KT-SM scale subdomains medication adherence, CV risk reduction, and ownership were put in the last block, and the total vaariance explained by the model as a whole was 26%,

$F(8, 142) = 6.10$, $p < .001$. However, the R^2 change was not significantly improved by entering any of these three variables, $\Delta R^2 = .00$, sig. F change = .64. Looking at the final model in Table 47, only gender ($\beta = .25$, $p < .001$) and square root-transformed SCQ ($\beta = -.19$, $p < .05$) had statistically significant beta coefficients. The results suggest that subjects' gender and comorbidity score were predictors for appearance. Male participants cared less about transplant-related appearance changes than females, while participants who reported higher scores on comorbidity (SCQ) also were dissatisfied with their appearance.

Table 47

Sequential Multiple Regression Analysis Summary for Variables Predicting Subscale: Appearance

Predictor	R^2	ΔR^2	*B*	SE	β	*t*
Step 1						
Gender			.56	.18	.24**	3.15
Age			.02	.01	.23**	3.02
Sqrt-SCQ			-.31	.09	-.26***	-3.55
	.19	.19***				
Step 2						
Gender			.60	.17	.25**	3.44
Age			.01	.01	.15*	2.03
Sqrt-SCQ			-.20	.09	-.17*	-2.24
PAM-13			.01	.01	.14	1.57
SEMCD			.10	.06	.16	1.76
	.25	.06**				
Step 3						
Gender			.60	.18	.25**	3.42
Age			.01	.01	.14	1.62
Sqrt-SCQ			-.22	.09	-.19*	-2.38

Table continues

PAM-13			.01	.01	.10	1.04
SEMCD			.10	.06	.15	1.54
M. adherence			.16	.14	.10	1.14
CV risk			.06	.11	.05	.57
Ownership			-.06	.16	-.03	-.37
	.26	.01				

Note. $n = 152$.
$^{*}p < .05$. $^{**}p < .01$. $^{***}p < .001$.

KTQ-25 subscale emotion. To determine the best equation model for predicting scores on the emotion subscale, three model compositions and results are presented in Table 48. Model 1 comprises variables of age, years of pre-transplant dialysis, and SCQ, explaining 16% of the variance in the emotion subscale, $F(3, 147) = 9.71$, $p < .001$. PAM-13 and SEMCD then were added in the model and accounted for 30% of the variance, $F(5, 145) = 12.16$, $p < .001$. Model 3 incorporated eight predictors including the KT-SM subdomains CV risk reduction, ownership, and skin cancer prevention and accounted for a total of 33% of the variance, $F(8, 142) = 8.90$, $p < .001$. Including the three KT-SM variables in the model slightly improved the R^2 increment, $\Delta R^2 = .04$, sig. F change < .05. Examining the final model, SEMCD ($\beta = .44$, $p < .001$), age ($\beta = -.21$, $p < .01$), and CV risk reduction ($\beta = .21$, $p < .05$) had statistically significant beta coefficients; SEMCD had the heaviest beta weight, meaning it had more impact than the other two variables. Recipients who were younger or performed more CV risk reduction behaviors reported experiencing less emotional distress.

Table 48

Sequential Multiple Regression Analysis Summary for Variables Predicting Subscale: Emotion

Predictor	R^2	ΔR^2	*B*	SE	β	*t*
Step 1						
Age			.03	.01	.28**	3.74
Year of dialysis			-.18	.09	-.14	-1.91
Sqrt-SCQ			-.33	.10	-.26**	-3.44
	.17	.17***				
Step 2						
Age			.02	.01	.19**	2.63**
Year of dialysis			-.14	.09	-.11	-1.58
Sqrt-SCQ			-.15	.10	-.11	-1.51
PAM-13			-.01	.01	-.11	-1.29
SEMCD			.32	.07	.46***	4.91
	.30	.13***				
Step 3						
Age			.02	.01	.21**	2.67
Year of dialysis			-.12	.09	-.10	-1.41
Sqrt-SCQ			-.17	.10	-.13	-1.72
PAM-13			-.01	.01	-.09	-.98
SEMCD			.31	.07	.44***	4.62
CV risk			.33	.13	.21*	2.55
Ownership			-.18	.19	-.08	-.95
Skin cancer			-.20	.15	-.12	-1.34
	.33	.04*				

Note. $N = 151$
*$p < .05$. **$p < .01$. ***$p < .001$.

In summary, the six regression models composed of characteristics, clinical factors, and SEMCD explained significant amounts of variation in the overall KTQ-25 (47%) and the subscales physical symptoms (42%), fatigue (43%), uncertainty/fear (19%), appearance (26%), and emotion (33%). The results are depicted in Table 49. However, the PAM-13 and KT-SM scale were not statistically significant in predicting scores for the overall KTQ-25 and four of the five subscales, except KT-SM domain CV

risk reduction. It is noteworthy that the subscale appearance was predicted by gender and SCQ (number of comorbidities) only; PAM-13, SEMCD, and KT-SM did not explain any variability in the subscale appearance. Although adding the KT-SM and PAM-13 in the regression did not reach statistical significance in explaining the variation in the overall KTQ-25 and four of the five subscales, as presented in Table 49, a significant amount of variance in the KTQ and five subscales were explained by six regression models. Therefore, the investigator concluded that H^5 was partially met.

Table 49

Six Equation Models for Predicting Overall KTQ-25 and 5 Subscales

Outcome	Predictor	% of variance explained
Overall KTQ-25	β_0 (constant) + β_1 (Gender) + β_2 (SCQ) + β_3 (SEMCD)	47%
Physical symptoms	β_0 + β_1 (high school or less) + β_2 (some college degree) + β_3 (SCQ) + β_4 (SEMCD)	42%
Fatigue	β_0 + β_1 (gender) + β_2 (SCQ) + β_3 (SEMCD)	43%
Uncertainty/fear	β_0 + β_1 (Age) + β_2 (SEMCD)	19%
Appearance	β_0 + β_1 (gender) + β_2 (SCQ)	26%
Emotion	β_0 + β_1 (Age) + β_2 (SEMCD) + β_3 (CV risk reduction)	33%

H^6. Criterion-related validity will be supported as the 16-item KT-SM total scale and five domain scales are statistically significantly correlated with the PAM-13, SEMCD, and KTQ-25 and 5 subscales.

H^6 about criterion-related validity was partially supported. Bivariate correlation coefficients of the KT-SM and the five domains with SEMCD and PAM were adequate, ranging from r =.22 to .53 ($p < .01$), and r = .31 to .52 ($p < .01$), respectively. KT-SM total was positively correlated with KTQ total and four of the five subscales (r = .23 to 32, $p < .01$), except the subscale uncertainty/fear. KT-SM domain medication adherence

was positively related to KTQ total and the subscales physical symptoms and appearance (r = .16 to 24, p < .05). The KT-SM domain CV risk reduction was positively related to all subscales except uncertainty/fear, and r ranged from .25 to .34. Protecting kidney was not statistically significantly related to the overall KTQ-25 and its subscales. Ownership was positively correlated with overall KTQ-25 and the five subscales, with Pearson's r ranging from .17 to .31, p < .05. Skin cancer was positively correlated with KTQ total and the physical symptoms, fatigue, and emotion subscales (r = .21 to 33, p < .05). Based on the results reported above, hypothesis 6 is determined to be partially supported.

Summary. The six models comprised of subject characteristics, clinical variables, PAM-13, SEMCD, and the overall KT-SM scale and five domains explained 47%, 42%, 43%, 19%, 26%, and 33% of the variance in the overall KTQ-25, physical symptoms, fatigue, uncertainty/fear, appearance, and emotion subscales, respectively (Table 50). Overall, only one KT-SM domain (CV risk reduction) significantly contributed to predicting the KTQ emotion subscale, β = .21, p < .05. PAM-13 was not statistically significant in predicting overall KTQ or any of the subscales in the six equation models. SEMCD was the strongest predictor for predicting overall KTQ-25 scale and four of the five subscales except the subscale appearance. For ease of further discussion in the next chapter, the six best-fitting models for predicting the overall KTQ-25 scale and five subscales are presented in Table 49. Summary tables for evaluating the psychometric properties of the KT-SM scale and five domains are displayed in Table 50 and Table 51.

Table 50

Evaluation of Psychometric Properties of KT-SM Scale and 5 Domains

Outcome	Cronbach alpha[a]	Inter-item correla-tion[b]	Item-total correla-tion[c]	Factor analysis[d]	Criterion validity[e]: PAM-13	Criterion validity[e]: SEMCD
KT-SM total	X	X	X	X	X	X
M. adherence	X	X	X	X	X	X
CV risk	X	X	X	X	X	X
Protecting kidney	X	X	X	X	X	X
Ownership	X	X	X	X	X	X
Skin cancer	X	X	X	X	X	X

[a]Cronbach's alpha > .70. [b]IIC > 3.4. [c]Item-to-total correlation > 3.8. [d]loading size > .40. [e]r = .22 to .53, $p < .05$.

Table 51

Evaluation of Psychometric Properties of KT-SM Scale and 5 Domains: Sequential Multiple Regression

Testing variable	Construct validity: Multiple regression[a]	Construct validity: Multiple regression[b]
KT-SM total	X	
Meds adherence	X	
CV risk reduction	X	X
Protecting kidney	X	
Ownership	X	
Skin cancer	X	

[a]Testing hypothesis 7 with PAM-13 and SEMCD; variances explained by the regression models were 45%, 32%, 18%, 21%, 37%, and 29%, respectively; $p < .05$. [b]Testing hypothesis 8, KTQ-25 as outcome; CV risk domain alone explained 5% of the variance in the KTQ-25 subscale emotion.

Summary

Chapter Four described the recruitment process and presented the results of the study beginning with a description of the data collection methods. Using SPSS, the

investigator examined the participant surveys for missing data and checked for outliers and data distribution. The aims, hypotheses, and research questions were discussed, and the factor analysis presented. Each section concluded with an analysis summary for variables predicting subscales. The concluding chapter, Chapter Five, discusses the study findings including the cost and effectiveness of Facebook recruitment for studies. It concludes with study limitations, implications for future research, and conclusions.

CHAPTER FIVE

DISCUSSION

This chapter begins with a summary of the study findings, followed by discussions of the cost and effectiveness of Facebook recruitment; issues related to the online survey; sample composition and clinical characteristics; Aim 1: content validity; Aim 2: internal consistency reliability; Aim 3: EFA results; and Aim 4: construct validity. The limitations of the study, implications for future research, and conclusions are presented as well.

Summary

The KT-SM scale, developed as part of this study to measure post-transplant SM behaviors in U.S. kidney recipients ($N = 153$ recruited from Facebook), demonstrates adequate internal consistency reliability as well as content and construct validity. The 16-item KT-SM scale is a multi-dimensional scale that contains five domains: medication adherence, protecting kidney, CV risk reduction, ownership, and skin cancer prevention. The KT-SM scale uses a 5-point Likert-type scale format with responses ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). Items are summed to produce an overall SM score (16 items) as well as five subscale scores to represent the five domains.

The ability to assess KT recipients' SM behaviors is critically important for clinicians and researchers; thus, the development of a psychometrically sound instrument has widespread research and clinical implications. The best treatment option for people with end-stage kidney failure is KT, but life after KT is complex and patients may be unprepared or underprepared to manage post-transplant health conditions. The 10-year allograft survival rate has not significantly improved over the past several decades

(Wekerle et al., 2017); thus, there is a critical need to promote KT SM behaviors and assess the relationships between SM behaviors and long-term graft outcomes. It is expected that the psychometrically sound KT-SM instrument developed in this study will allow researchers to collect and evaluate data related to SM behaviors, which is particularly important for testing interventions that aim to improve post-transplant SM behaviors.

The second purpose of the study was to evaluate construct validity via hypothesized relationships among sSM, self-efficacy, patient activation, and HRQoL. As hypothesized, greater self-efficacy and high patient activation level were positively correlated to post-KT SM behavior and quality of life. The multivariate regression analysis results indicated that SM behaviors may be predicted by knowing a KT recipient's patient activation level and perceived self-efficacy. Higher levels of patient activation and self-efficacy result in better SM behaviors. Thus, interventions that are designed to improve patient activation and/or self-efficacy may result in improved SM behaviors. Given the study results using the adapted conceptual model as a guide, there may be multiple areas (SM, patient activation, and self-efficacy) to intervene in improving SM behaviors. Designing and evaluating an intervention that may have particular effects on a specific outcome may be difficult without fully understanding the phenomenon related to KT SM. The framework adapted for KT SM serves as a map that may guide the design and implementation of interventions and systematically evaluate intervention outcomes on KT SM behavior, patient activation, and self-efficacy (De Silva et al, 2014; Hurley et al., 2015; Van Belle, Marchal, Dubourg, & Kegels, 2010).

Effectiveness of Facebook Recruitment and Survey Incentive

Participants were recruited mainly by means of paid Facebook ads (51%; Figure S-1; Appendix S), pay-to-promote study page (Appendix J) and recruiting posts (7.8%), and recruiting messages (Figure T-1; Appendix T) on three targeted KT Facebook support groups (34%). The pay-to-promote study page and pay-to-boost recruiting post function were not as effective in recruiting participants as standard Facebook ads in this study. The Kidney Transplant Facebook study page reached 1,933 people, generated 164 likes, was shared by 21 Facebook users, and received 15 clicks on the study link during the 5-week data collection period, but only 12 respondents self-reported that they found our study via the Facebook study page.

A total of 538 respondents who saw the Facebook ads visited the REDCap Kidney Transplant Study survey page (Appendix M), and 292 read the study information sheet and submitted a valid email address. Of these 292 respondents, 9% declined to participate in the study, leaving 265 respondents who agreed to be informed and screened for eligibility. A total of 153 usable and completed surveys were generated within a 5-week recruitment period. Of these, the mean missing item rate of these surveys was less than 5%. The study results showed that Facebook recruitment using standard ads combined with a small guaranteed post-paid incentive did facilitate a shorter subject recruitment time and a lower missing item rate. The overall yield rate of 28% (n = 153/538) is acceptable and consistent with recent reported online survey response rates of 22.89–23.43% (Tustin, Crowcroft, & Gesink, 2017). Tustin et al. (2017) collected 1,096 completed surveys in 4 weeks using CPM (cost per 1,000 impressions) with a lifetime budget of Canadian $1,500 (approximately U.S. $1,170); however, Tustin et al.'s target

sample was the general population and their campaign budget was 6.69 times higher than the present study's budget. When the targeted participants come from the general population, Facebook ads using CPM seem to reach more potential participants effectively. However, when the research subjects come from a hard-to-reach or small population, pay-per-click (PPC) appears to be more cost effective for subject recruitment per the present study findings.

Cost of Facebook Recruitment

The total cost for Facebook standard ads and the Kidney Transplant Survey study page promotion was $206. Of that, $35 was paid for the Facebook study page promotion and post-boosting service. The average costs for acquiring each valid survey were $2.19 through Facebook standard ads and $2.92 from the study page (see Table 52). As noted previously, the Facebook standard ad was pay-per-click; therefore, payment was made only when users clicked the ad. Page promotion and post-boost were impression-based. By Facebook's definition, each time the study page or posts about the study page were displayed in Facebook users' newsfeed counts as impressions. Reach is the number of people who saw the page or page post (Facebook Help Center, n.d.). Even though the study page reached 1,933 people, only 12 respondents were recruited from the study page. In addition, the Facebook study page required more time to create and maintain. When taking time and cost into consideration, the Facebook page and post promotion were not as cost- and time-efficient as the pay-per-click-based Facebook standard ads. Still, the study results supported findings from previous studies that Facebook is a viable, cost-efficient subject recruitment tool for hard-to-reach populations in health-related

research (Carter-Harris, Ellis, Warrick, & Rawl, 2016; Jones, Lacroix, & Porcher, 2017; Lohse & Wamboldt, 2013).

Table 52

Cost for 5 Weeks Facebook Standard Ads, Post Boosting, and Page Promotion

Promotion type	Number of surveys acquired	Cost	Cost per person
Facebook standard ads	78	$171	$2.19
Pay-to-promote Facebook study page + Pay-to-boost post	12	$35	$2.92

Issues Related to REDCap Online Survey

Although Facebook recruitment of respondents was adequate, several issues arose that future studies should address. The reminder messages did not work as effectively as expected. This could be attributed to two reasons. First, the REDCap system requires two different 6-digit codes for two-step verification to resume a survey. Although a step-by-step procedure with screenshots was provided in the reminder emails, respondents could still have considered that it was a burden to resume the survey. Second, according to the monthly report sent from the Facebook business department, 95% of this study's respondents saw the Facebook ads while using mobile devices and only 5% saw the ads while using laptop or desktop computers. It was highly likely that the survey respondents were taking the survey on tablets or smartphones. Because the survey design included scrolling and visual display not optimized for mobile devices, survey fatigue may have resulted due to the smaller mobile device screen.

Studies have shown that mobile device users have a higher survey dropout rate, more missing items, longer survey response times, and shorter answers to open-ended

questions, and they are more likely to be distracted by other things than computer users (Antoun, Couper, & Conrad, 2017; Lugtig & Toepoel, 2016; Wenz, 2017). The trend of using mobile devices to take internet surveys is growing, and modifications of survey tools for mobile devices are necessary (Antoun et al., 2017; Revilla, Toninelli, Ochoa, & Loewe, 2016; Wang et al., 2017). For future studies, online survey design should be optimized for mobile devices to account for different screen sizes, web browsers, and operating systems to attract and retain the highest number of participants (Leiner, 2013; Revilla et al., 2016).

Threats to Validity: Misrepresentation, Response Time, and Response Pattern

Offering a guaranteed post-paid incentive without precautions to prevent unqualified participants from taking the survey to obtain the incentive could be a threat to online survey data quality. For example, the PI noticed that a respondent took repeated surveys, submitting 25 surveys with 25 different Gmail addresses during a 1.5-hour period. Observing the survey start and end times showed that each survey submission was in sequence with a short break in between. The mean completion time of these surveys was between 1–3 minutes. These 25 surveys had a similar response pattern, and the provided emails had similar naming conventions. Those surveys were found to use a random pattern or picking middle response option on most of the scales and demonstrated logical inconsistency. These surveys also were identified as extreme outliers by statistical procedures and eliminated from the data set. If this potential participant had submitted surveys at different times (as opposed to a relatively short period of time) it is unlikely that he/she would have been identified as having submitted multiple surveys instead of just one.

Survey response time and response pattern are the major indicators for assessing internet data quality. REDCap is a powerful data-collecting platform that can export data directly into formats that are compatible with major statistical packages and, therefore, reduce data entry error. However, in this case, lack of internet protocol tracking and blocking functions made the data cleaning procedure take longer. The PI had foreseen these problems and made every effort to prevent misrepresentation. These precautions included putting screening questions in the survey to eliminate unqualified respondents, including screening questions with multiple choices, and limiting each respondent to one email address only. As internet-based survey methods are used increasingly in health-related research, the experience/knowledge gained from past traditional survey methods such as postal survey or phone survey may not be entirely applicable to this field. Experts suggest that putting *screener* questions or *bogus* items in the survey could help identify careless responses or respondents who are misrepresenting as eligible (Meade & Craig, 2012; Oxtoby, King, Sheridan, & Obst, 2016). A screener question asks for a specific answer format for a question; a respondent who fails to answer correctly could be considered a careless survey respondent. Similarly, a bogus item is a question with a clear answer, such as "are there 31 days in February?" Meade and Craig (2012) suggest incorporating a bogus item for every 50 items but not exceeding more than 3 such items in a survey. Carter-Harris et al. (2016) utilized a simple but effective method to prevent misrepresentation: they used a traditional postal mail survey reward to the addresses provided. Further studies are needed to help researchers to identify and prevent misrepresentation, to set gold standards for survey response time, and to decide what types of response patterns can be considered meaningless data.

Sample Composition and Clinical Characteristics

Most participants in this study were married, female, White, employed, and had received higher education. The study results are consistent with results reported in previous KT studies except for gender. The KT literature has shown that there are gender and racial disparities in access to KT. Specifically, men, Whites, and individuals with a college degree are more likely to get a KT (Epstein et al., 2005; Goldfarb□Rumyantzev et al., 2012). Nearly 65% of participants in this study were female, which is consistent with recent studies using Facebook as recruiting tool that reported ranges of 56% to 80.8% female (Kayrouz et al., 2016; Nelson, Hughes, Oakes, Pankow, & Kulasingam, 2014; Thornton, Harris, Baker, Johnson, & Kay-Lambkin, 2016). This may be because females engage more often in activities on social network sites such as Facebook and are more willing to participate in online survey than males (Adam, Manca, & Bell, 2016; Shepherd, 2016). In addition, African Americans have been found to be less likely to participate in internet surveys than those of other races (Keusch, 2015).

The average years post-transplant for the present sample was 6.94 years (*SD* = 6.65), and nearly 73% of subjects had a history of pre-transplant dialysis, with an average of 2.89 years (*SD* = 3.2). About 54% (*n* = 84) of the present subjects received kidneys from living donors. Approximately 92% of respondents reported having at least one comorbidity, and the average number of comorbidities reported was 2.46 (*SD* = 1.86). The present study's results are consistent with previous observations; 47%–91% of kidney recipients reported at least one comorbidity in previous studies (Hollisaaz et al., 2007; Machnicki et al., 2011).

A total of 55% of participants in this study reported having back pain or arthritis pain. Masajtis□Zagajewska and colleagues (2011) conducted a study on the prevalence and characteristics of pain in KT recipients and found that 64% of the KT recipients in their study (*n* = 73) reported pain, and 93% of KT participants reported pain intensity that was moderate to severe. The most common pain locations were calf (44%), abdomen (34%), head (30%), and back (29%). Among those who reported having pain, 41% of KT recipients did not take any pain relievers but just endured the pain. Failure to treat pain can negatively impact HRQoL, but little is known about the prevalence, characteristics, and intensity of pain in this population. How KT recipients manage their pain also remains understudied (Masajtis□Zagajewska et al., 2011). A large-scale study of pain in this population is needed.

Aims

Aim 1

The first aim was to evaluate content validity. The original 40-item scale was reviewed by four content experts for concept definition, item relevance, wording clarity, and item appropriateness. The CVI for the final 29 items was .93 after removing 11 items with CVI scores less than .75. Some items with CVI = .75 were modified for wording and kept because they were theoretically important and generated based on KT practice guidelines. The KT-SM is comprehensive but concise and does not place undue burden on participants.

Aim 2

The second aim of this study was to estimate the internal consistency reliability of a new instrument, the KT-SM scale, among adult KT recipients. The overall coefficient

alphas for the initial 29- and reduced 16-item KT-SM Scale were .89 and .84, respectively. The alpha coefficients for the 16-item scale were .83, .70, .72, .77, and .72 for the subscales medication adherence, CV risk reduction, protecting the new kidney, ownership (partnership) in post-transplant care, and skin cancer prevention, respectively, demonstrating adequate internal consistency reliability. It is recommended to report item-to-total correlation, inter-item correlation, and internal coefficient reliability per subscale for a multidimensional scale (Netemeyer et al., 2003). The corrected item-to-total correlation coefficients were greater than .38 for all items in each subscale. The mean inter-item correlation coefficients for the five subscales were in the range of .38 to .63, which suggests strong correlation among items yet no multicollinearity present (Pallant, 2013). It is well known that Cronbach's alpha value is affected by scale length, but the short version of the 16-item KT-SM scale still achieved a desirable alpha value of .84. The item analysis results support the reliability of the reduced 16-item KT-SM scale. However, there is a concern pertaining to reliability.

The reliability concern is that a ceiling effect was noted in the present sample. A ceiling effect occurs if an item has more than 33% of responses reaching the highest possible score (Paxton, Fithian, Stone, & Silva, 2003). Some items present a higher ceiling effect but were retained in the scale for this study phase based on the following rationales. One measure administered in different settings and populations can result in variance in the psychometric proprieties. For example, Bot et al. (2004) reported ceiling effects for the United Kingdom Shoulder Disability Questionnaire when it was administered to people with shoulder pain from a community sample but saw no ceiling effects among patients who sought care in the primary care setting. Furthermore,

respondents recruited from the internet tend to select extreme response options such as *strongly agree*, resulting in a ceiling effect. Leach, Butterworth, Poyser, Battham, and Farrer (2017) investigated physical and mental health issues in postpartum women, using internet recruitment (n = 1,083) and face-to-face recruitment as part of a nationwide study (n = 579). The study result showed that participants recruited from the internet tend to provide an overestimate compared to the national sample. Subjects from the internet sample reported more physical and mental health problems than the national representative sample after adjusting for socio-economic factors. The present study is exploratory in nature and the sample was recruited from Facebook, so further testing with a larger sample size and recruiting from various settings is recommended (Bruce, Fries, Lingala, Hussain, & Krishnan, 2013; Hinkin, 1995).

Aim 3

The third aim of this study was to estimate the dimensionality of the KT-SM scale through EFA. As presented in Chapter Four, the EFA results demonstrated that the KT-SM scale consisted of five factors with loadings ranging between .39 and .89. However, the 16 items did not load exactly as hypothesized in the the five domains; only medication adherence and protecting kidney domains remained the same. The item "limit alcohol" was originally developed for the hypothesized subscale, CV risk reduction, as CV disease is a leading cause of death in the KT population (Mathur et al., 2017). Yet, the item "limit alcohol" was grouped in the subscale, protecting kidney, per EFA results. Excessive alcohol consumption leads to developing CV disease as well as decreases kidney function (Nakagawa & Hasebe, 2017; Shankar, Klein, & Klein, 2006). A failing transplanted kidney can result in returning to dialysis, and dialysis means losing freedom

because of the need for dialysis several times weekly (Gill & Lowes, 2014). Perhaps that was the reason why the survey participants prioritized preserving allograft function.

The items "I keep every appointment with my transplant doctor" and "I keep my blood (lab) test appointments" formed a new domain. These two items initially were placed in the hypothesized subscale, protecting kidney. The two items are unique in that they are not correlated with any items in the scale. Based on the characteristics of these two items, the domain was "ownership (partnership) in post kidney transplant care" (Bodenheimer, Wagner, & Grumbach, 2002) There has been little research on KT recipients' perception about ownership (partnership). For future study, a clear conceptual definition of ownership (partnership) in this population will be required. Moreover, two items may insufficient to capture the meaning of ownership from KT recipients' perspective; therefore, items pertaining to the concept need to be added to the subscale for further testing.

Aim 4

The fourth aim of this study was to estimate the criterion validity and construct validity of the KT-SM scale. Criterion-related validity was evidenced by significant correlations of the KT-SM and domains with SEMCD (r =.22 to .53, p = .01), PAM (r = .31 to .52, p = .01), and the overall KTQ (r = .20 to .32, p = .01) except for one KT-SM domain: protecting kidney. Construct validity was supported by multivariate regression analysis results. The linear combination of age, patient activation, and self-efficacy explained 45% of the variance in KT-SM behaviors, while 47% of the variance in KTQ (measuring quality of life) was predicted by age, comorbidity, and self-efficacy. The detailed discussions are divided into two sections: criterion validity–bivariate correlations

among all study variables and construct validity–factors/variables that predict overall KT-SM and five domains and overall KTQ-25 and five subscales.

Criterion validity of the 16-item KT-SM scale was evidenced by significant correlation with PAM-13 ($r = 52$, $p < .001$), SEMCD ($r = .50$, $p < .001$), and KTQ-25 total scores ($r = .32$, $p < .001$). In addition, the intercorrelations of the domains medication adherence ($r = .59$, $p < .001$), CV risk reduction ($r = .76$, $p < .001$), protecting kidney ($r = .75$, $p < .001$), ownership ($r = .51$, $p < .001$), and skin cancer prevention ($r = .76$, $p < .001$) with the KT-SM total scale were statistically significant. These findings that SM behavior is positively associated with patient activation (PAM-13), self-efficacy, and HRQoL are consistent with those of studies conducted in heart failure, diabetes, multiple sclerosis, chronic kidney disease, and KT populations (Goodworth et al., 2016; Jacobson et al., 2017; Johnson et al., 2016; Tharavanij et al., 2008; Weng et al., 2013, Young et al., 2017; Zimbudzi, Lo, Ranasinha, Kerr, Polkinghorne et al., 2017). Because the KT-SM scale and KTQ-25 are multidimensional scales, the investigator further examined and highlight the findings from bivariate correlations of the KT-SM's five domains with the KTQ-25 subscales specifically.

Bivariate correlations of KT-SM five domains with KTQ-25 subscales. In all, the KT-SM and five domains were partially correlated with the KTQ-25 and its five subscales. In particular, "medication adherence" related positively to the KTQ-25 subscales physical symptoms ($r = .16$, $p < .05$) and appearance ($r = .24$, $p < .05$). Previous studies have shown that perceiving fewer medication and cosmetic side effects is positively associated with long-term treatment adherence (Chisholm□Burns, Pinsky

et al., 2012; Gonzalez et al., 2007). Moreover, KT recipients who experience poor life quality tend to be nonadherent to medications (Chisholm□Burns, Erickson et al., 2012).

KT-SM domain CV risk reduction was positively related to the KTQ-25 subscales physical symptoms, fatigue, appearance, and emotion, ranging from $r = .20$ to .34, $p < .05$. Items in domain CV risk reduction are related to exercising regularly, healthy diet, and lifestyle modification. Multiple studies have shown that exercising regularly is associated with better emotional well-being, less depressive syndrome, better sleep quality, improved muscle strength and physical function, and ultimately improved quality of life in KT recipients (Barroso et al., 2016; Bernstein & McNally, 2017; Chan et al, 2016; Galanti et al., 2016; Latimer-Cheung et al., 2013; Takahashi et al., 2018). In addition, regular exercise can help maintain healthy weight and increase self-esteem and body esteem (Homan & Tylka, 2014; Klaassen et al., 2017). The present study results were not different from previous reports.

KT-SM domain ownership correlated to all the KTQ-25 subscales, ranging between $r = .17$ and .31, $p < .05$. As mentioned previously, little is known about ownership/partnership of post-transplant SM in this population. Chisholm□Burns, Erickson et al. (2012) conducted a study with 512 adult KT recipients to examine factors related to medication non-adherence, and the results suggested that lower life satisfaction, feeling a loss of control over one's life, and being less satisfied with care received and care providers were associated with IS medication non-adherence. By contrast, KT recipients who had greater control over their lives, such as the ability to manage daily routines and keep medications refilled, were satisfied with their lives, care quality, and care providers, and therefore, adherent to treatments.

KT-SM domain skin cancer prevention was related positively to the KTQ-25 subscales physical symptoms ($r = .33$, $p < .01$), fatigue ($r = .21$, $p < .05$), and emotion ($r = .23$, $p < .01$). The relationships among these variables seem illogical. However, the key words in the domain skin cancer prevention include outdoor activity, sun, and sunscreen, and all these link to exercise or physical activity. As noted previously, the benefits of exercise include increased emotional well-being, decreased physical fatigue, and improved physical functioning. In the present study results, the more kidney recipients practiced skin cancer precaution, the less likely they were to complain of physical symptoms, fatigue, and emotional distress.

KT-SM domain protecting kidney was not correlated with any subscale of the KTQ-25. The purpose of practicing kidney-protecting behavior is to preserve allograft function, and allograft function is tied to post-transplant quality of life. Upon further examination of each item in the KTQ-25 and the domain protecting kidney, the KTQ-25 is more likely to measure physical symptoms rather than to assess kidney recipients' perceived quality of life, so future study should be conducted on the relationships between HRQoL and kidney-protecting behaviors using different scale measures such as the SF-12/SF-36.

Bivariate correlations of PAM-13, SEMCD, and KTQ-25. The relationship between PAM-13 and SEMCD was statistically significant, $r = .53$, $p < .001$, which is consistent with the recent study by Young et al. (2017). Nevertheless, the bivariate correlational analysis for PAM-13 and KTQ-25 and its five subscales indicated that PAM-13 was only weakly related to the KTQ-25 total scale ($r = .22$, $p < .01$) and its subscales physical symptoms ($r = .20$, $p < .05$) and appearance ($r = .24$, $p < .01$). In

contrast, there were moderate to strong associations of SEMCD with the five KTQ subscales, ranging from $r = .35$ to $r = .61$, $p < .01$. The prior study results for the relationships of PAM-13 and HRQoL were mixed. Hibbard et al. (2007) and Magnezi et al. (2014) reported a positive relationship between quality of life and PAM-13. Conversely, Goodworth et al. (2016) found that patient activation was not statistically significantly related to HRQoL in the multiple sclerosis population.

Overall, the correlation coefficients for KT-SM and its five domains, PAM-13, and SEMCD were statistically significant. However, while estimating correlation coefficients with outcome variable HRQoL (KTQ-25), the KT-SM scale and its five domains was partially correlated with KTQ-25 and its five subscales, and PAM-13 was weakly related to KTQ-25 total and two subscales.

Construct Validity

KT SM Behavior as Outcome

KT-SM overall. The linear combination of age ($\beta = .27$; $p < .001$), years post-transplant ($\beta = -.25$; $p < .001$), SEMCD ($\beta = .28$; $p < .001$), and patient activation ($\beta = .32$; $p < .001$) explained 45% of the variance in the overall KT-SM scale scores. In other words, KT recipients' SM behavior was predicted by knowing their age, patient activation level, and perceived self-efficacy level. In contrast, the longer the time post-transplant, the less recipients were performing self-managing behavior. Knowledge, skills, and social support are essential elements for individuals to engage in SM behavior (Ryan & Sawin, 2009). For future study, adding knowledge and social support in the regression may help to explain additional proportions of the variance in KT-SM behavior. To the best of the investigator's knowledge, this is the first study to examine the

associations among patient activation, self-efficacy, and SM behaviors in kidney recipients. Still, further testing is needed with a large-scale sample and including measures of knowledge and social support will further understanding of relation between SM behaviors and quality of life.

Variables that predict medication adherence score. The final equation model for predicting medication adherence containing age (β = .30; $p < .001$), years post-transplant (β = -.19; $p = .009$), years of pre-transplant dialysis (β = .15; $p < .05$), and PAM-13 (β = .29; $p < .001$) accounted for 32% of the variance in medication adherence, $p < .001$. These results were not different from those previously reported in the research on diabetes, oncology, and KT (Griva et al., 2012; Parchman, Zeber, & Palmer, 2010; Salgado et al., 2017).

Variables that predict CV risk reduction score. Age, years post-KT, duration of pre-transplant dialysis, and self-efficacy were found to significantly predict CV risk reduction practice, accounting for 23% of the variance in CV risk reduction score. This result is consistent with the results of other studies that a higher level of perceived self-efficacy was associated with lifestyle modification including exercising regularly and eating a well-balanced diet (Alharbi et al., 2017; Greco et al., 2014; Steca et al., 2013; Zelber-Sagi et al., 2017). Mathur et al. (2017) investigated all causes of post-KT hospitalization (n = 103,118) from 2005 to 2011 and found that 26.5% of incidences were related to CV disease. Diabetes and high blood pressure are well-known risk factors for CV disease; in the present sample, 60.8% (n = 93) of the participants reported having high blood pressure, 25.7% had diabetes, and 11.8% had heart disease; this is not different from other recent findings (Ballesteros et al., 2017). CV risk increases over time

after transplant and is the leading cause of death in KT patients. However, the importance of post-KT CV risk factors is less addressed with KT recipients, and education to increase awareness of post-transplant CV disease and risk factors in the KT population is crucial (Ballesteros et al., 2017)

Variables that predict protecting kidney score. The final regression model composed of years post-transplant (β = -.24, $p < .01$) and patient activation (β = .36, $p < .001$) explained 21% of the variance in the protecting kidney score. Years post-transplant is a well-known risk factor for non-adherence behaviors in this population (Dew, Dabbs, & DiMartini, 2017), and the findings of this study is consistent with previously reported findings. Recent study results suggest that higher PAM level is associated with better control of diabetes clinical indicators such as blood pressure, cholesterol, and triglyceride level (Sacks et al., 2017). Maintaining behavioral change is always challenging. KT recipients need specific knowledge and confidence in self-managing lifetime post-transplant care. Intervention to increase patient activation level may help strengthen and sustain KT recipients' medication adherence and kidney-protecting behaviors.

Variables that predict ownership. The regression model demonstrated that age (β = .29, $p < .001$), being single/divorced (β = -.24, $p < .001$), and SEMCD (β = .20, $p < .001$) made unique contributions in predicting the ownership score, accounting for 37.2% of the variance. The domain ownership incorporated two items: "keep doctor's appointments" and "keep blood test appointments"; these two items have a meaning of but are not limited to "appointment adherence." Appointment adherence is an independent risk factor for allograft loss, while allograft function is positively related to HRQoL (Taber et al., 2017). Appointment adherence can be detected by clinicians and is

considered a more reliable method to assess medication adherence (Taber Fleming et al., 2017). The current study indicated that being single or divorced was a negative predictor for ownership of post-transplant care. KT recipients who are single or divorced are usually considered to lack social support, perceive more stress, experience lower quality of life, and tend to be more less adherent to treatment than those who are married/living with a partner (Frazier, Davis-Ali, & Dahl, 1995; Ladin, Daniels, Osani, & Bannuru, 2018). In addition, older age and greater self-efficacy were positively associated with ownership. These findings are consistent with the previous literature (Kauric-Klein et al., 2017; Náfrádi, Nakamoto, & Schulz, 2017). The current study results suggest that interventions targeted at promoting patient activation and self-efficacy may increase KT recipients' perceived post-KT ownership.

Variables that predict skin cancer prevention. Years of pre-transplant dialysis ($\beta = -.17$, $p < .05$), self-efficacy ($\beta = .34$, $p < .001$), and patient activation ($\beta = .18$, $p < .05$) make unique contributions to predict the score of skin cancer prevention and accounted for 29% of the variance. In the present study, participants who had been on pre-transplant dialysis longer performed fewer skin cancer precautions. Long-term dialysis is associated with deterioration of physical function because of fatigue, decreasing muscle mass, not being encouraged to exercise due to concerns about leak and hernia associated with the peritoneal dialysis catheter, and a gradually more sedentary lifestyle (Findlay & Mark, 2017; Johansen, 2007; Morishita, Tsubaki, & Shirai, 2017; Thangarasa, Imtiaz, Hiremath, & Zimmerman, 2017). Some KT recipients may mistakenly believe that because they stay indoors most of time there is no need to practice skin cancer prevention behavior. Nonetheless, KT recipients, patients with

ESRD, and dialysis recipients who have an immunosuppressed/immunocompromised status are at higher risk of immune-deficiency-related cancers (Stewart et al., 2009).

Little is known about the associations between patient activation, self-efficacy, and preventive health behaviors. The present study results show that patient activation is related to skin cancer preventive behavior ($r = .37$, $p < .0001$) and is one of three independent contributors in predicting skin cancer prevention behavior. More studies are needed to confirm the relation. Findings of Heckman et al.'s study (2011) affirmed that skin cancer preventive behavior was predicted by greater perceived self-efficacy ($\beta = .17$, $t = 2.55$, $p = .012$). Other recent study findings showed that an intervention to increase skin cancer prevention knowledge ($\beta = .24$, $p < .05$) predicted the frequency of practicing cancer-preventive behaviors (DiMillo et al., 2017; Werk, Hill, & Graber, 2017). However, transplant recipients' knowledge and awareness regarding transplant-related cancer risk and preventive behavior are still understudied (Patel et al., 2017). Interventions to increase cancer awareness and knowledge, motivate patients to perform monthly skin self-exams, and prolong the intervention effect in this population are crucial.

Post-Transplant Quality of Life (KTQ-25) as Outcome

The purpose of the present study is to psychometrically test the KT-SM scale. The sequential regression analysis results showed that self-efficacy is a strong predictor of scores on the KTQ-25 overall and its five subscales, but the KT-SM total score and four of the five domain scores and the PAM-13 did not reach statistical significance in predicting the KTQ-25 score. Therefore, this discussion is focused only on results pertaining to the KT-SM scale.

The KTQ emotion score was predicted by a linear combination of age (β = .21, $p < .01$), self-efficacy (β = .44, $p < .001$), and KT-SM domain CV risk reduction (β = .21, $p < .05$). The present results are no different from prior findings (Calia et al., 2017). Emotional distress has been found to impede diabetes patients from performing SM behavior (Schinckus, Dangoisse, Van den Broucke, & Mikolajczak, 2017). Similarly, in KT patients, emotional distress is associated with negative health behaviors including missing clinic and lab appointments and medication non-adherence (Griva, Neo, & Vathsala, 2018; Penkower et al., 2003); therefore, reducing emotional distress may result in better SM behaviors (including CV risk reduction practice) and consequently improve transplant outcomes. However, the ways KT recipients identify stressors and adapt to distress remain understudied. Early and routine screening for emotional distress such as depression may help to identify problems early and thereby provide the support KT recipients need to manage emotion (Griva et al., 2018; Ndemera & Bhengu, 2017; Veater & East, 2016).

Theoretical and Research Implications

The contributions of the study include the following highlights. First, the results of the analyses show that KT SM is a multidimensional construct; in particular, the EFA results showing five domains support the multidimensionality of the KT-SM scale. Moreover, the KT-SM scale provides researchers a means to capture specific post-KT SM behaviors so that more effective and individualized interventions can be designed and delivered to kidney recipients accordingly. This will ultimately improve long-term KT outcomes. Second, the present study is the first to investigate and identify the significant

relationships among the five domains of post-KT SM behaviors, patient activation, self-efficacy for managing chronic disease, and HRQoL.

While there has been increasing attention paid to KT SM, there was very little framework/theory that could be used to describe SM and HRQoL in this population at the time of study preparation. Nevertheless, the framework used to guide the study was found to be useful in predicting/explaining phenomena in KT SM behavior and quality of life. In this framework, KT recipients' perceived self-efficacy and patient activation level were hypothesized to be positively related to SM behaviors, and engaging in SM behaviors was hypothesized to ultimately result in improved HRQoL. The hypothetical links of the study variables were evidenced by the results of bivariate correlational analysis and multivariate regression analysis.

Still, two important variables are not included in this conceptual model: knowledge and social support. Skills, knowledge, and social support are crucial components for individuals to engage in and sustain SM behavior (Ryan & Sawin, 2009). Inclusion of knowledge may help explain an additional proportion of variance in KT SM behavior, as previous study results indicated that KT recipients are underprepared for their post-transplant care by the current discharge program, especially in terms of knowledge regarding IS medication, CV risk reduction, skin cancer prevention, and protecting kidney behaviors (Ghadami, Memarian, Mohamadi, & Abdoli, 2012; Patel et al., 2017; Vasquez, Tanzi, Benedetti, & Pollak, 2003; Williams, Tong et al., 2012).

Social support is an indicator of allograft outcomes and medication adherence; inadequate social support will make a person ineligible for a transplant. Some researchers simply use marital status as a measure of social support, but many factors have been

found to be negatively related to kidney recipients' marital status following transplant, such as the complex treatment regimen, appearance changes due to medication side effects, sexual dysfunction, emotional distress due to fear of rejection, and the financial burden from the high cost of IS medications (Crawford, Low, Manias, & Williams, 2017; Evans et al., 2010; Pisanti, et al., 2017; van Ek et al., 2017). In the present study results, being single or divorced was a negative predictor of the domain ownership. A possible explanation for this is that ownership of post-KT care included keeping doctor's and lab appointments and may require a spouse/relative/partner to help with transportation or household chores when the recipient is away from home. Researchers have suggested that social support is equally important in post-transplant evaluation as in pre-transplant assessment (Ladin et al., 2018). Incorporating knowledge and social support in the framework guiding future studies may help further the understanding of factors that may hinder or enhance KT recipients' SM behavior and quality of life after transplant.

Lastly, the EFA results revealed a new domain ownership, but this topic has not been thoroughly investigated in KT research. The investigator's bivariate correlational analysis results indicated that ownership of post-KT care was positively significant related to KTQ-total (r =.31; p < .01) and the subscales physical symptoms (r =.29; p < .01), fatigue (r =.29; p < .01), uncertainty/fear (r =.17; p < .05), appearance (r =.23; p < .05), emotion (r =.20; p < .05); PAM-13 (r =.42; p < .001), and SEMCD (r =.36; p < .001). This means that KT recipients who perceive a higher level of ownership of post-KT care scored higher on overall HRQoL, reported fewer physical symptoms, experienced less fatigue, were more satisfied with their appearance, were not as emotionally distressed, adapted and engaged in post KT SM behavior, and perceived

greater self-efficacy. Moreover, ownership is impacted negatively by more comorbidities and by being divorced/single. Based on results from the present study, further testing and interventions targeting post KT care will warrant further investigation in KT SM and quality of life.

Research and Clinical Implications

The 16-item KT-SM scale has the following advantages for clinical practice. First, the statistical analysis results provided preliminary evidence of the reliability and validity of the 16-item KT-SM. Second, the KT-SM scale is concise but comprehensive, incorporating five domains necessary to detect post-KT SM behaviors. Third, the item wordings, meanings, and 5-point Likert-type response options are straightforward, easy to read and respond to, and can be completed by KT recipients within 3 minutes. Lastly, items in the scale were evidence-based and generated per recommendations of the KDIGO Clinical Practice Guideline for the Care of KT Recipients (Kasiske et al., 2010) and from the National Kidney Foundation, thus, there are no culture adaptation issues, which means the scale has potential to be used in countries outside the U.S.

Risk factors associated with non-adherence behavior and being less likely to perform SM behaviors were identified in the present study, which may help clinicians to target individuals who are at high risk of non-adherence. Utilizing the KT-SM scale design, a post-KT care plan can be tailored according to each individual's skill. Moreover, the current study results have shown that more years post-transplant is associated with medication non-adherence and less practice of kidney-protecting precautions and overall SM behavior. Interventions focused on prolonging the intervention effect and helping KT recipients maintain the recommended health behaviors

will be crucial. Future studies to identify a cutoff score to separate those with adequate verus inadequate SM behaviors may be helpful for targeted and tailored interventions.

Limitations

This study has some limitations that must be acknowledged. First, this is a cross-sectional study with a convenience sample of 153 subjects recruited from Facebook. The study was not intended to identify causality, so the investigator does not consider the cross-sectional design to be a study limitation. Still, as most of the participants were female, selection bias could be an issue. Another limitation is that nearly 45% of subjects were recruited from two Facebook KT support groups and one KT exercise group. People who perceived more social support and who exercise regularly have been found to have greater self-efficacy and higher confidence levels, and this may affect the interpretation of the results. Third, all data were self-reported, and the study results/estimations could be inflated. Fourth, concurrent validity cannot be supported as there is no other KT SM scale specifically developed for KT recipients in the U.S. Finally, the last hypothesis was only minimally supported. The variation in HRQoL was not explained by PAM-13 and four of the five domains of the KT-SM scale. However, this could be attributed to the outcome measure selected.

Future Directions

Given the exploratory nature of this study, two types of future research should be pursued: psychometric testing of the 16-item KT-SM scale and theory testing. Scale refinement may be required to include other domains. This study's results suggest that pain is still an issue for KT recipients, so incorporating pain management in the KT-SM scale may give some indications of how to help improve KT recipients' quality of life.

Moreover, the ownership of post-KT care is an important concept that has not been adequately addressed in KT research. A clear conceptual definition of ownership is needed so that items can be generated based on the definition and added into the domain for testing. To further test the psychometric properties of the KT-SM scale, confirmatory factor analysis and test-retest reliability analysis with a large sample recruited from clinical settings is required. In addition, a cut-off value for predicting adequate post-KT SM behaviors needs to be identified.

The present study results show that 55% of the proportion of variance in KT SMt behaviors was not explained by the regression model: the linear combination of β_0 (constant) + β_1 (age) + β_2 (years post-transplant) + β_3 (PAM-13) + β4 (SEMCD). Adding measures of knowledge and social support for further testing may push understanding of post-KT SM even further. The causal relationships for the variables of the adapted KT framework need to be further identified using path analysis. In addition, the statistical analysis suggests that self-efficacy mediated the effects of patient activation and SM behavior on HRQoL. It is not clear if the mediating effect is caused by an unobserved confounding of variable or variables, so future testing using path analysis is strongly recommended.

Conclusion

The KT-SM is a newly developed instrument to evaluate SM behaviors in U.S. kidney recipients. The study results provide beginning evidence of reliability as well as content and construct validity. Instruments like this will provide a means to capture the SM behaviors of the KT population, which is critical for future work on interventions. In addition, the framework guiding this study was found to be useful in explaining

phenomena in KT SM. Designing and implementing interventions and evaluating outcomes using a theory-driven approach will ensure that the intervention is effective for kidney recipients

APPENDIX A

PERMISSIONS TO USE

From: Young, Lufei <l >
Sent: Thursday, June 28, 2018 8:15 AM
To: Chung, Shu-Yu
Subject: RE: [EXTERNAL] Dr. Young, please help!

Dear Shu-Yu

Here are the published articles, original model and citations. I am interested to see how this model can be used in other population. Please don't hesitant to contact me if you need more information. I am very happy to help with your dissertation preparation in anyway. Best, Lufei

1. **Young, L**., Barnason, S., & Do, V. (2015). Promoting self-management through adherence among heart failure patients discharged from rural hospitals: A study protocol [version 2; referees: 2 approved, 1 approved with reservations]. *F1000Research, 3,* 1-14. doi:10.12688/f1000research.5998.2

2. **Young, L**., Hertzog, M., & Barnason, S. (2016). Effects of a home-based activation intervention on self-management adherence and readmission in rural heart failure patients: the PATCH randomized controlled trial. *BMC Cardiovascular Disorders, 16*(1), 176.

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Figure A-1. Permission to Use Zimmerman (and Young) Framework.

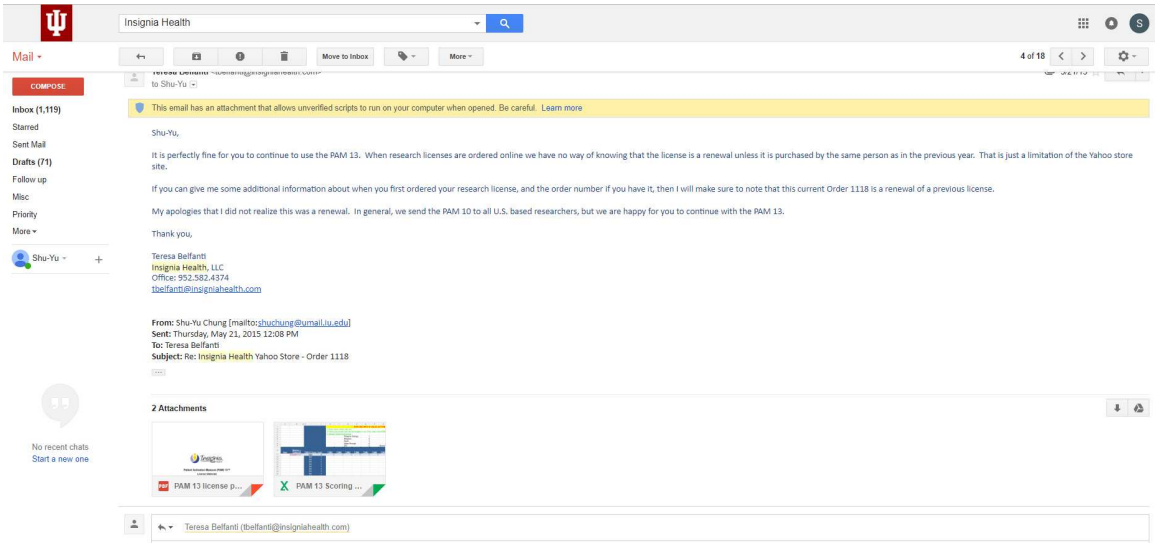
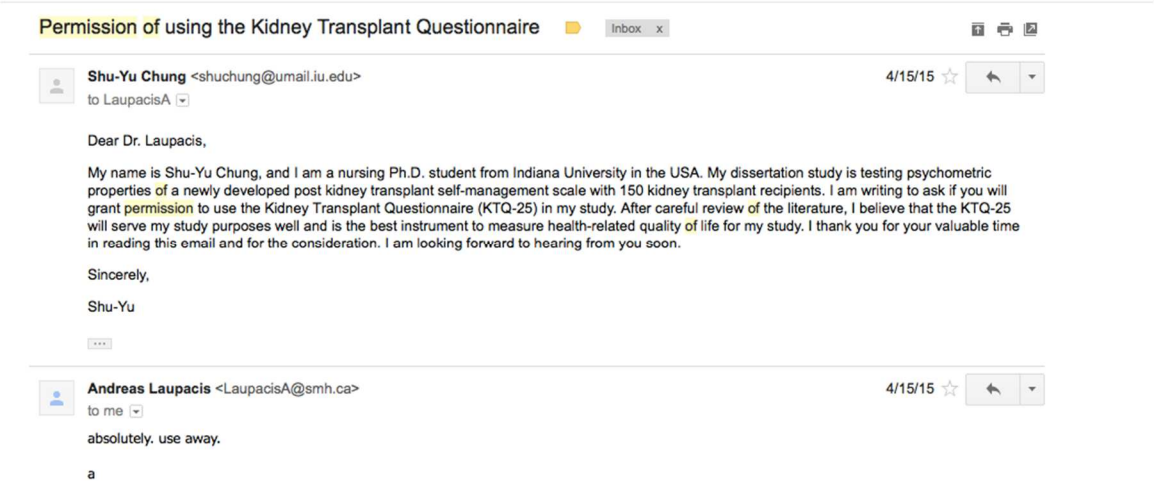


Figure A-2. Permission to Use the PAM.



Permission of using the Kidney Transplant Questionnaire Inbox x

Shu-Yu Chung <shuchung@umail.iu.edu> 4/15/15
to LaupacisA

Dear Dr. Laupacis,

My name is Shu-Yu Chung, and I am a nursing Ph.D. student from Indiana University in the USA. My dissertation study is testing psychometric properties of a newly developed post kidney transplant self-management scale with 150 kidney transplant recipients. I am writing to ask if you will grant permission to use the Kidney Transplant Questionnaire (KTQ-25) in my study. After careful review of the literature, I believe that the KTQ-25 will serve my study purposes well and is the best instrument to measure health-related quality of life for my study. I thank you for your valuable time in reading this email and for the consideration. I am looking forward to hearing from you soon.

Sincerely,

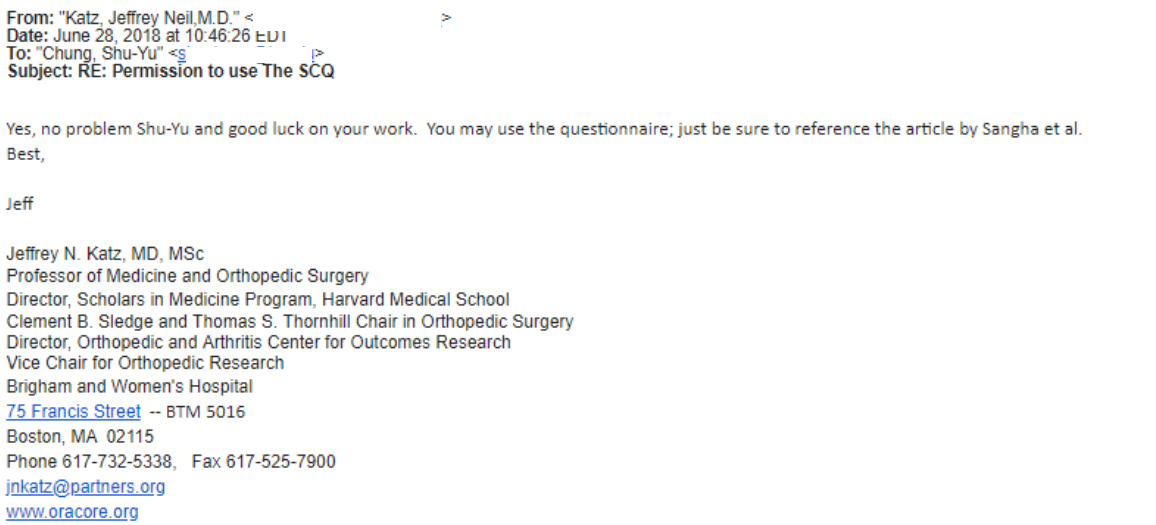
Shu-Yu

Andreas Laupacis <LaupacisA@smh.ca> 4/15/15
to me

absolutely. use away.

a

Figure A-3. Permission to Use the KTQ-25



From: "Katz, Jeffrey Neil,M.D." <
Date: June 28, 2018 at 10:46:26 EDT
To: "Chung, Shu-Yu" <s
Subject: RE: Permission to use The SCQ

Yes, no problem Shu-Yu and good luck on your work. You may use the questionnaire; just be sure to reference the article by Sangha et al.
Best,

Jeff

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Figure A-4. Permission to Use the SCQ.

APPENDIX B

SURVEY 5: DEMOGRAPHIC

1. What is your age? _____ years old
2. What is your gender?
    - O Male
    - O Female
3. What is your current marital status?
    - O Married
    - O Living with a partner
    - O Never married
    - O Separated/divorced
    - O Widowed
4. What is your race/ethnicity?
    - O African-American
    - O Asian/Pacific Islander
    - O Caucasian/White
    - O Hispanic/Latin
    - O Other, please specify:_____
5. What is the highest level of education you have completed?
    - O Less than high school
    - O High school, diploma, or GED
    - O Some college
    - O College graduate
    - O Some graduate work
    - O Graduate degree
6. What is your current employment status?
    - O Retired
    - O Unemployed
    - O Employed full-time
    - O Employed part-time
    - O Other. Please specify: _____

APPENDIX C

SURVEY 6: MEDICAL HISTORY

1. How long were you on dialysis before your kidney transplant surgery?
   Please specify: _____

2. How many years has it been since you had your kidney transplant?
   Please specify: _____

3. What type of kidney transplant did you have?
   - O Living donor-Related
   - O Living donor-Non-Related
   - O Non-living donor

APPENDIX D

SURVEY 7: THE SELF-ADMINISTERED COMORBIDITY QUESTIONNAIRE

The following is a list of common medical problems. If you have been told by a medical doctor that you have any of these problems, please indicate it in the first column. If you do not have the problem, skip to the next problem.

If you do have the problem, please indicate in the second column if you receive medications or some other type of treatment for it.

In the third column, please indicate if the problem limits any of your activities.

Finally, indicate any medical conditions you may have that are not listed under "other medical problems" at the bottom of this page.

Problem	Do you have the problem?		Do you receive treatment for it?		Does it limit your activities?	
	No (0)	Yes (1)	No (0)	Yes (1)	No (0)	Yes (1)
Heart disease such as heart attack or poor heart function						
High blood pressure						
Lung disease						
Diabetes						
Ulcer or stomach disease						
Liver disease						
Anemia or other blood disease						
Cancer						
Depression						
Osteoarthritis or degenerative arthritis						
Back pain						
Rheumatoid arthritis						
Other medical condition 1						
Other medical condition 2						
Other medical condition 3						

Your completed questionnaire has been received. Thank you!
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APPENDIX E

KIDNEY TRANSPLANT SELF-MANAGEMENT ITEM POOL: RESULTS OF COGNITIVE INTERVIEWING

Table E-1

Kidney Transplant SM Item Pool: Results of Cognitive Interviewing

Items	Feedback from think-aloud interview	Decision
Medication Management		
1. I take my antirejection pills as instructed by my transplant doctor.	All participants agreed that the statement is easy to understand and answer.	Item retained
2. I call my transplant team when I have new side effects from my antirejection pills.	M1 and M2: It would be more clear if it can be written more specifically, like side effects: rashes, dry throat, dizzy, headache, fever, etc. M2 and F2 said that they have never experienced any side effects. F1 suggested using "anything different," "I am not used to," or "my med makes me sick." F2 suggested using "I don't feel well after taking my pills" to replace "side effects."	According to "Prograf" (medication manufacturer), transplant patients should call if they have: fever, flu symptoms, sore throat, short of breathing, pain on urinating, blood in urine, etc. Two participants claimed that they have never experienced any side effects, so they don't know what the side effects of the pills are. In addition, patients may not be able to remember all medication side effects; therefore, "anything different", "I am not used to", or "my med makes me sick" would be easy for most people to answer.
3. I change the number of antirejection pills when my kidney is working well.	All participants agreed that the statement is easy to understand and answer. But one participant rated this item as not important because no transplant patient should self-medicate without doctor's approval.	Item revised based on the following reasons: 1. Response item for this item is opposite from that of other items, needs add extra SAS syntax for this item. 2. Easy for participants to answer since other items are "positive wording."

Table continues

			3. "I do not change the number of antirejection pills even when my kidney is working well:" Two participants rated this revised item as better than the old version.
4.	I use a method, like a pillbox or reminder, to remind me to take my antirejection pills.	5 participants use a pillbox or phone reminders to help them remember to take medications. M1 is a young man, and only underwent dialysis for 3 years. He has no comorbidities, so he simply takes immunosuppressive medication once in the morning, once at night. M3 said, "I use my memory."	Item retained
5.	I refill my prescriptions on time. (How do you define on time? How easy or difficult is it for you to remember to refill your meds?)	M1 defined "on time" as refilling one week before running out of antirejection pills. And CVS calls. M2 said that the university hospital pharmacy delivers all medication to his door every single month. "I put meds at four locations: car, office, home, and backpack" and "reserve extra meds." M3 & F3: "3 to 4 days before it ran out." "Pharmacy calls." F1: Pharmacy calls, but "sometimes I forgot." F2: "reserve at least 2 weeks meds" and "easy to figure out from the pillbox"	Item retained
6.	I never forget to take my antirejection pills.	M1: "Never" but admitted taking pills at times that are slightly different from what the doctor prescribed. M2: Never M3: Forgot to take pills sometimes, about "3 times per year"	Item retained

Table continues

		F1: "Yes, I did forget" but "my husband helps me to remember." F2: only forgot once many years ago	
7.	I tell my transplant doctor about problems and concerns with my pills during every clinic visit.	M3: sometimes negotiates with the transplant doctor to see if his antirejection pills dose can be decreased. "If the doctor disagreed, I will still take meds as prescribed." M2 & F2 have never had any side effects from antirejection pills, but they agreed that they will tell their doctors if they have something uncommon. F3: "Absolutely"	Item retained
8.	I avoid taking herbs and NSAIDS like ibuprofen and Motrin.	All participants suggested that using the full name "nonsteroidal anti-inflammatory drugs" would be better. And provide an example of an herb to help them answer this question.	A double-barreled question, revising item
9.	I avoid eating and drinking grapefruit and grapefruit juice	This new item was suggested by 4 participants	Grapefruit increases the levels of immunosuppressant in the blood and can mislead transplant doctors' decision on medication dosing.
Diet Management			
1.	I eat a low cholesterol diet.	None of the participants could tell the difference between low cholesterol and low fat diets. Items 1 and 2 are confusing to them.	Item 1 removed and use "I eat low-calorie foods" instead. Weight gain is a big issue after kidney transplant; studies have shown that weight gain can be prevented or manage with diet management,
2.	I eat a low fat diet.		Item 2 is kept and provided with examples
3.	I eat a low sodium(salt) diet.	F1: No MSG F2: low sodium food is fresh food, no canned food, no frozen food F3: "I eat fresh food," "I avoid canned food."	According to the National Kidney Foundation, most transplant recipients still need to limit salt intake, but it depends on their conditions and what their doctors told them.

Table continues

			Immunosuppressive medication such as steroids may cause fluid retention and raise blood pressure, therefore the item is kept but revision is needed.
4.	I monitor how much sodium I eat.	M1 monitors sodium intake amount because he used to be a dialysis patient. M2: never because "my kidney is working well"	Item 3 and 4 are very similar, so item 4 removed
5.	I read food labels.	F2: "If I am going to eat at a restaurant, I pick low salt with no extra sauce on it." She pays attention to sodium content when she prepares food or eats at restaurant. M1: reads food label. F3: reads food labels only if it is canned food, but she avoids canned food most of time	It is not required for kidney transplant recipients to read food labels unless they are told to.
6.	I avoid raw and undercooked food such as: meats, seafood, salad bar, and eggs, etc.	M1: "medium well steak, I like pink inside" M2: "Avoid salad bar" All participants were able to provide correct examples of raw and undercooked food.	Item retained
Lifestyle Modification			
1.	I exercise 3 times per week for 20 minutes.	M1 exercises 5 days per week. M2 exercises 25 minutes every day and agreed that adding "at least" would be better. F2 exercises once or twice a week. F3 exercises 3–5 times per week depending on how busy she is during the week: "I exercise because I don't want to gain weight."	National Kidney Foundation suggests exercise 5 times per week for 30 minutes. Item revised.

Table continues

2.	I avoid alcoholic drinks.	All participants refrained from alcohol except F2, who is an occasional drinker, less than 2 oz every 2 weeks. She suggested the item could be revised as "I limit my alcoholic drinks."	I have discussed this with the transplant coordinator. From their standpoint, all transplant patients should refrain from alcohol consumption. Guidelines say "limit alcohol intake."
Graft Function Monitoring			
1.	I check my feet or ankles for swelling every day.	M1 & M2 check feet or ankle swelling every day. F1: "I don't check it everyday, but I know if my shoes are tight	
2.	I take my blood pressure every day.	M3 & F2 don't check items 2–4 every day because they had their transplants done more than 10 years ago, but they agreed that for new transplant patients these items should be checked daily.	
3.	I take my temperature every day.	M2, M3, F2, F3 never check temperature, or only check if they don't feel well	
4.	I check my weight every day.	Only 2 participants check their weight everyday	KT recipients are asked to call if they have gained 2-3 pounds in one day or 5-7 lbs. within 3-5 days. Item revision is needed.
5.	I call my transplant doctor if my urine output changes.	M2: "yes, I keep track of how much I lose". He suggested that urine color change should be added into the item pool as well. F1: Defined urine output change as: "how much I am going to the bathroom." F3: Did not really know how many times she urinates everyday	"Urine output" is more like a medical term; meaning of changes can refer to decrease or increase. Item needs to be revised.

Table continues

Infection Prophylaxis

1.	I keep track of symptoms of infections when I have them. (What, to you, are the symptoms of infection?)	M1: fever M2: running temp M3: "skin infection", "not feeling well" F1: "fever", "UTI", "pain on urinating." Stated that she has been hospitalized for UTI in the past. F2: "hard to answer"	"Keep track of symptoms of infections" was confusing patients, additional explanations were given for all participants
2.	I drink at least eight 8-ounce glasses of water (2 liters) every day.	All participants agreed this item is clear and easy to answer. F3 drinks a lot of fluids including tea, coffee, and water but does not know how much water she takes every day.	Item retained
3.	I avoid close contact with people who are sick.	M2: Avoid handshake with sick people. Use sanitizer if needed. M3: Avoid coughing people. "I wear a mask if necessary." F2: "stay away from coughing people", "not shake their hands"	Item retained
4.	I wash my hands after using the bathroom and before meals.	M2 uses sanitizer as needed. F3 washes her hands with soap and water before preparing meals and after cooking.	Standard hand washing is washing hands with soap and water
5.	I keep appointments with my transplant doctor.	All participants agreed items 10 & 11 are important.	No change needed
6.	I keep my lab test appointments. (What were you thinking when I asked this item?)	M2 also checks lab results at the hospital website or through hospital smartphone application.	No change needed

Table continues

		M3: “Blood tests” F2: “It helps the doctor to know what is going on” F3 stated that without lab data, there is not much the doctor can do during the appointment. “creatinine levels”	
Skin Cancer Prevention			
1.	I use sunscreen when outdoors.	All participants agreed this is important	
2.	I wear a hat to protect my skin when outdoors.	All participants agreed this is important	
3.	I wear protective clothing to protect my skin when outdoors.	All participants agreed this is important	
4.	I self-check my whole body skin every month.	All participants agreed this is important	
5.	I have my annual skin exam check by a dermatologist.	None of them have done this.	Retained because this is recommended by kidney transplant practice guidelines & National Kidney Foundation

APPENDIX F

KT-SM RESULTS OF EXPERT REVIEW (Total CVI = 0.931)

Table F-1

KT-SM Results of Expert Review (Total CVI = 0.931)

Proposed Items	CVI
Medication management (7 items)	
1. I take my antirejection pills as instructed by my transplant doctor.	1.00
2. I call my transplant team if my antirejection pills make me sick.	1.00
3. I do not change the number of antirejection pills, even when my kidney is working well.	1.00
4. I use a pill box or other reminder to remember to take my antirejection pills.	1.00
5. I tell my transplant doctor about problems and concerns with my antirejection pills.	1.00
6. If any doctor other than my transplant doctor gives me a new medication, I will call my transplant doctor to make sure it is safe to take.	1.00
7. I avoid taking nonsteroidal anti-inflammatory drugs (NSAIDS) like ibuprofen, naproxen, or Motrin.	1.00
Diet Recommendation (5 items)	
8. I avoid eating sweets, fried foods and other high calorie foods most of the time.	0.75
9. I eat low fat foods like chicken, poultry, lean meats, or low-fat dairy products most of the time.	0.75
10. I watch how much sodium (salt) I eat.	0.75
11. I read food labels most of the time.	1.00
Lifestyle Modification (2 items)	
12. I exercise for at least 30 minutes 5 times per week.	0.75
13. I limit alcoholic drinks to no more than one drink per day.	1.00
Graft Monitoring (6 items)	
14. I take my blood pressure as instructed by my doctor.	1.00
15. I look at my feet and ankles to check for swelling as instructed by my doctor.	1.00
16. I call my transplant team if I gain 2–3 pounds in one day.	0.75
17. I call my transplant doctor if I urinate (pee) less than usual.	1.00
18. I keep almost every appointment with my transplant doctor.	1.00
19. I keep my blood (lab) test appointments.	1.00
Infection prophylaxis (6 items)	
20. I call my transplant doctor when I have signs of an infection like fever, flu-like symptoms, pain on urinating or a cough.	1.00
21. I take my temperature as instructed by my doctor.	1.00
22. I drink at least eight 8-ounce glasses of water (2 liters) every day.	1.00
23. I avoid close contact with people who are sick.	1.00
24. I wash my hands with soap and water after using the bathroom.	1.00
25. I wash my hands with soap and water before meals.	1.00

Table continues

Skin Cancer Prevention (6 items)

26.	I use sunscreen when outdoors.	1.00
27.	I wear a hat to protect my skin when I am outside.	0.75
28.	I examine (look at carefully) at my skin and lips at least once a month.	0.75
29.	I call my transplant doctor if there is a change or suspicious lesion on my lips or skin.	0.75

APPENDIX G

SURVEY 3: SELF-EFFICACY FOR MANAGING CHRONIC DISEASE 6-ITEM SCALE

Table G-1

Survey 3: Self-Efficacy for Managing Chronic Disease 6-Item Scale

We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

	1 Not at all confident	2	3	4	5	6	7	8	9	10 Totally Confident
1. How confident do you feel that you can keep the fatigue caused by your disease from interfering with the things you want to do?	1	2	3	4	5	6	7	8	9	10
2. How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?	1	2	3	4	5	6	7	8	9	10
3. How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?	1	2	3	4	5	6	7	8	9	10
4. How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?	1	2	3	4	5	6	7	8	9	10
5. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce you need to see a doctor?	1	2	3	4	5	6	7	8	9	10
6. How confident are you that you can do things other than just taking medication to reduce how much your illness affects your everyday life?	1	2	3	4	5	6	7	8	9	10

APPENDIX H

25-ITEM KIDNEY TRANSPLANT QUESTIONNAIRE

This questionnaire is designed to learn how you have been feeling during the last two weeks. You will be asked about how tired you have been feeling, how your mood has been, and what physical symptoms or problems you have experienced.

Please mark up to 6 problems or symptoms from the list that follows that you have experienced frequently during the last two weeks. If you have experienced more than 6, please mark the 6 that were most troublesome.

1) Loss of weight and muscle
2) Decreased mental ability
3) Itchy/dry skin
4) Infections
5) Hypotension
6) Embarrassment caused by appearance or access site
7) Aching, tired legs
8) Coughing during day or night
9) Very little strength
10) Side-effects from medications
11) Forgetfulness
12) Confusion
13) Aching bones
14) Trouble getting to sleep
15) Regulating bowel movements
16) Constipation or diarrhea
17) Vomiting
18) Headaches
19) Nausea or upset stomach
20) Shivering
21) Waking up during the night
22) Loss of appetite
23) Lightheadedness or dizziness during daily activities
24) Shortness of breath in daily activities
25) Decreased sexual ability
26) Difficulty focusing attention
27) Difficulty concentrating
28) Need to rest frequently because of shortness of breath
29) Increased appetite
30) Excessive weight gain
31) Acne
32) Trouble getting a good night's sleep
33) Muscle pain

Other: _____

1. Of the 6 items that you listed, please choose the problem that troubles you most and indicate how much trouble or distress you have had during the last two weeks by choosing one of the following options:

   1) A very great deal of trouble or distress
   2) A great deal of trouble or distress
   3) A good deal of trouble or distress
   4) A moderate amount of trouble or distress
   5) Some trouble or distress

6) Very little trouble or distress
7) No trouble or distress

2. Of the 6 items that you listed, please choose the problem that troubles you the second most and indicate how much trouble or distress you have had during the last two weeks by choosing one of the following options:

   1) A very great deal of trouble or distress
   2) A great deal of trouble or distress
   3) A good deal of trouble or distress
   4) A moderate amount of trouble or distress
   5) Some trouble or distress
   6) Very little trouble or distress
   7) No trouble or distress

3. Of the 6 items that you listed, please choose the problem that troubles you the third most and indicate how much trouble or distress you have had during the last two weeks by choosing one of the following options:

   1) A very great deal of trouble or distress
   2) A great deal of trouble or distress
   3) A good deal of trouble or distress
   4) A moderate amount of trouble or distress
   5) Some trouble or distress
   6) Very little trouble or distress
   7) No trouble or distress

4. Of the 6 items that you listed, please choose the problem that troubles you the fourth most and indicate how much trouble or distress you have had during the last two weeks by choosing one of the following options:

   1) A very great deal of trouble or distress
   2) A great deal of trouble or distress
   3) A good deal of trouble or distress
   4) A moderate amount of trouble or distress
   5) Some trouble or distress
   6) Very little trouble or distress
   7) No trouble or distress

5. Of the 6 items that you listed, please choose the problem that troubles you the fifth most and indicate how much trouble or distress you have had during the last two weeks by choosing one of the following options:

   1) A very great deal of trouble or distress
   2) A great deal of trouble or distress
   3) A good deal of trouble or distress
   4) A moderate amount of trouble or distress
   5) Some trouble or distress
   6) Very little trouble or distress
   7) No trouble or distress

6. Of the 6 items that you listed, please choose the problem that troubles you the sixth most and indicate how much trouble or distress you have had during the last two weeks by choosing one of the following options:

   1) A very great deal of trouble or distress
   2) A great deal of trouble or distress
   3) A good deal of trouble or distress
   4) A moderate amount of trouble or distress

5) Some trouble or distress
6) Very little trouble or distress
7) No trouble or distress

7. In the last two weeks, how much trouble or distress have you had because of excessive appetite?

1) A very great deal of trouble or distress
2) A great deal of trouble or distress
3) A good deal of trouble or distress
4) A moderate amount of trouble or distress
5) Some trouble or distress
6) Very little trouble or distress
7) No trouble or distress

8. In the last two weeks, how much trouble or distress have you had because of excessive hair growth?

1) A very great deal of trouble or distress
2) A great deal of trouble or distress
3) A good deal of trouble or distress
4) A moderate amount of trouble or distress
5) Some trouble or distress
6) Very little trouble or distress
7) No trouble or distress

9. In the last two weeks, how much trouble or distress have you had because of excessive weight?

1) A very great deal of trouble or distress
2) A great deal of trouble or distress
3) A good deal of trouble or distress
4) A moderate amount of trouble or distress
5) Some trouble or distress
6) Very little trouble or distress
7) No trouble or distress

10. In the last two weeks, how much trouble or distress have you had because of acne?

1) A very great deal of trouble or distress
2) A great deal of trouble or distress
3) A good deal of trouble or distress
4) A moderate amount of trouble or distress
5) Some trouble or distress
6) Very little trouble or distress
7) No trouble or distress

11. During the past two weeks, how often have you felt weak?

1) All of the time
2) Most of the time
3) A good bit of the time
4) Some of the time
5) A little of the time
6) Hardly any of the time
7) None of the time

12. How often during the past two weeks have you felt sluggish?

1) All of the time
2) Most of the time
3) A good bit of the time
4) Some of the time
5) A little of the time

6) Hardly any of the time
7) None of the time

13. During the past two weeks, how much trouble or difficulty have you had because of having very little strength?

1) A very great deal of trouble or difficulty
2) A great deal of trouble or difficulty
3) A good deal of trouble or difficulty
4) A moderate amount of trouble or difficulty
5) Some trouble or difficulty
6) Very little trouble or difficulty
7) No trouble or difficulty at all

14. During the past two weeks, how much trouble or difficulty have you had because of increased tiredness?

1) A very great deal of trouble or difficulty
2) A great deal of trouble or difficulty
3) A good deal of trouble or difficulty
4) A moderate amount of trouble or difficulty
5) Some trouble or difficulty
6) Very little trouble or difficulty
7) No trouble or difficulty at all

15. During the past two weeks, how often have you felt low in energy?

1) All of the time
2) Most of the time
3) A good bit of the time
4) Some of the time
5) A little of the time
6) Hardly any of the time
7) None of the time

16. How often during the past two weeks have you felt fear or panic related to rejection of the kidney?

1) All of the time
2) Most of the time
3) A good bit of the time
4) Some of the time
5) A little of the time
6) Hardly any of the time
7) None of the time

17. How often during the past two weeks have you felt uncertain about your future?

8) All of the time
9) Most of the time
10) A good bit of the time
11) Some of the time
12) A little of the time
13) Hardly any of the time
14) None of the time

18. How often during the past two weeks have you felt worried?

1) All of the time
2) Most of the time
3) A good bit of the time
4) Some of the time
5) A little of the time

6) Hardly any of the time
7) None of the time

19. How often during the past two weeks have you felt protective of your transplant?

1) All of the time
2) Most of the time
3) A good bit of the time
4) Some of the time
5) A little of the time
6) Hardly any of the time
7) None of the time

20. How often in the last two weeks have you felt depressed?

1) All of the time
2) Most of the time
3) A good bit of the time
4) Some of the time
5) A little of the time
6) Hardly any of the time
7) None of the time

21. How often during the past two weeks have you felt stubborn?

1) All of the time
2) Most of the time
3) A good bit of the time
4) Some of the time
5) A little of the time
6) Hardly any of the time
7) None of the time

22. How often in the last two weeks have you felt anxious?

1) All of the time
2) Most of the time
3) A good bit of the time
4) Some of the time
5) A little of the time
6) Hardly any of the time
7) None of the time

23. How often during the past two weeks have you felt impatient?

1) All of the time
2) Most of the time
3) A good bit of the time
4) Some of the time
5) A little of the time
6) Hardly any of the time
7) None of the time

24. How often in the last two weeks have you felt irritable or difficult to get along with?

1) All of the time
2) Most of the time
3) A good bit of the time
4) Some of the time
5) A little of the time
6) Hardly any of the time
7) None of the time

25. How often in the last two weeks have you felt generally frustrated?

    1) All of the time
    2) Most of the time
    3) A good bit of the time
    4) Some of the time
    5) A little of the time
    6) Hardly any of the time
    7) None of the time

APPENDIX I

REVIEW OF EXISTING POST-KT-SM SCALES

Table I-1

Review of Existing Post-KT-SM Scales

Author(s)/Year/ Location	Items	Self-management definition/frame work	Subscales	Validity & reliability	Limitations
Weng et al., 2010, Taiwan	27 items measured with a 5-point Likert-type scale: 0 (*never*) to 4 (*always*)	Yes Not reported	1. Problem-solving (10 items) 2. Patient-provider partnership (4 items) 3. Self-care behavior (13 items)	Cronbach's α for problem-solving, patient-provider partnership, and self-care behavior were 0.80, 0.70, and 0.81 respectively. 1. Construct validity statistic not reported	Only 1 item to measure medication adherence 1. No graft function monitoring 2. No diet management 3. No cancer precaution 4. Most items written as double or triple-barreled questions 5. Translation quality
Kosaka et al., 2013, Japan	24 items measured with a 4-point Likert-type scale: 1 (*not applied*) to 4 (*strongly applied*)	Yes No framework used	1. Self-monitoring (6 items) 2. Self-care behavior in daily living (7 items) 3. Early detecting and coping with abnormalities after kidney transplantation (4 items) 4. Stress management (3 items)	1. Cronbach's α coefficients for 4 subscales were from 0.61 (stress management) to 0.87. 2. The kappa coefficients for the additional 4 items were from 0.33 to 0.72. 3. Construct validity was confirmed.	1. No subscale for IS medication adherence, but the first three of four additional items are considered "medication adherence" items 2. Most items were too general to answer; ex: "I eat well-balanced meals" and "I keep my house clean" 3. No subscale for graft function monitoring 4. No lifestyle modification items such as exercise

Table continues

			5. Four items related to clinical importance were added to the scale		5. No cancer precaution items 6. Translation quality
Schmid-Mohler et al., 2014, Switzerland	44 items assessed with yes/no response option Self-management tasks in the first 2 years following kidney transplant	Yes/Yes Three sets of self-management tasks described by Corbin and Strauss (1988) and Lorig (2003)	1. Managing medication regimen 2. New life roles 3. Emotion management	Mixed-method No reliability and validity data reported.	1. Focused on emotion management tasks 2. At very early sate of instrument development, no sample questions provided in their study.
Ziegelmann et al., 2002, England	24-item transplant effects questionnaire with a 5-point Likert scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*)	No/No	1. Worry about transplant (6 items) 2. Guilt regarding donor (5 items) 3. Disclosure (3 items) 4. Adherence (5 items) 5. Responsibility (4 items)	1. Cronbach's α ranging from .72 to .86. Test-retest reliability had favorable results except for "disclosure" (Cronbach's α = .60). 2. Construct validity supported by principal components analysis and confirmatory factor analysis results.	4 of 5 subscales mainly focus on emotional responses and reactions to kidney transplant. Only the medication adherence subscale (5 items) is considered self-management related.

APPENDIX J

FACEBOOK STUDY PAGE

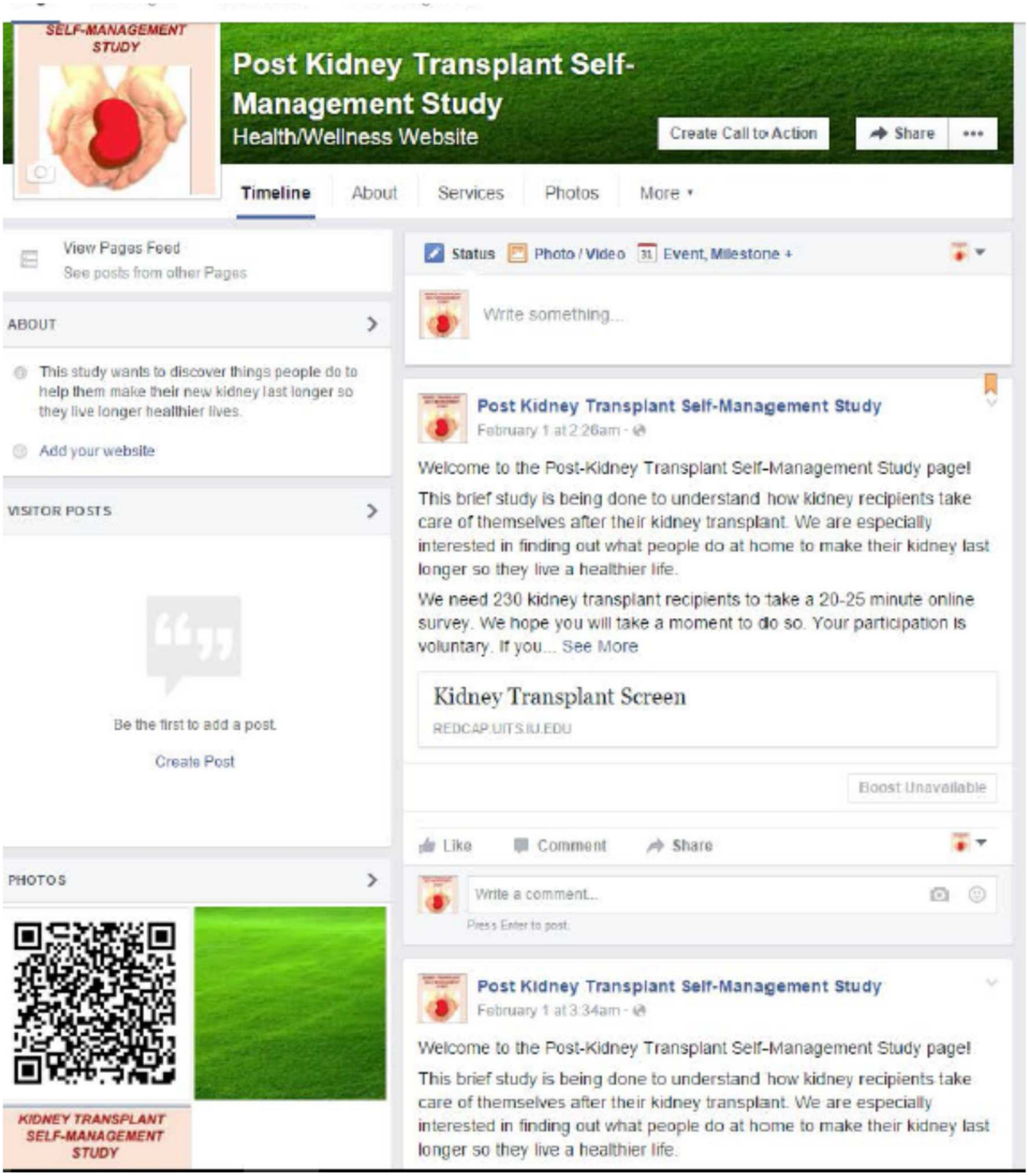

Figure J-1. Facebook Study Page.

APPENDIX K

FACEBOOK RECRUITMENT PERMISSIONS

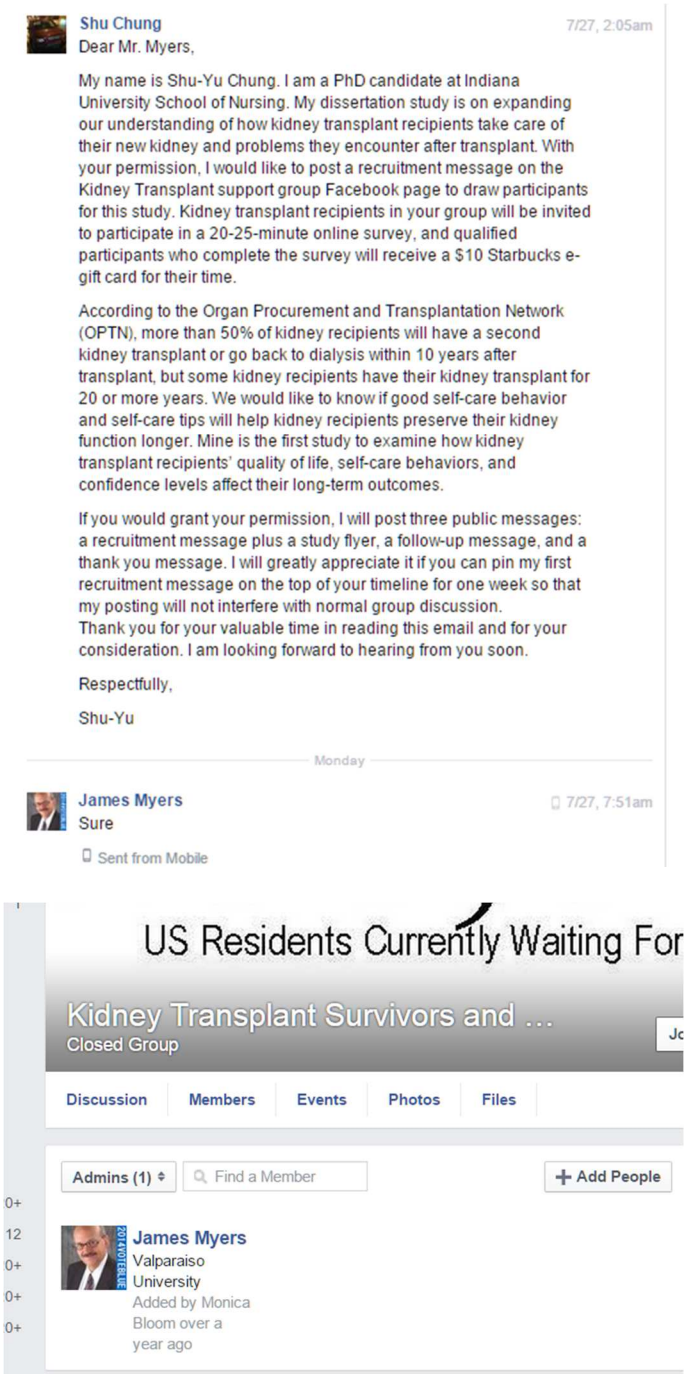

Figure K-1. Recruitment Permission from Facebook Support Group, Kidney Transplant Survivors and Donors.

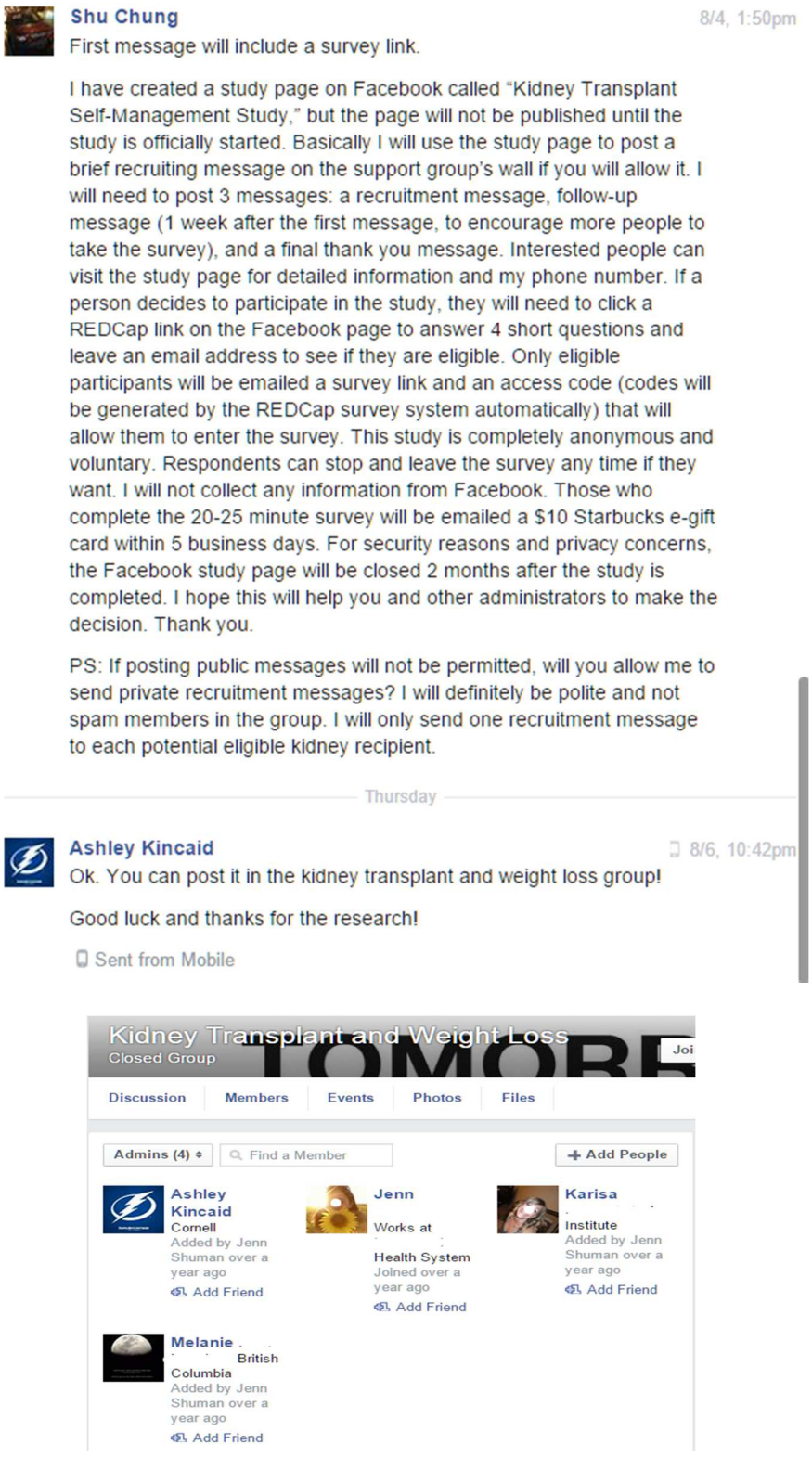

Figure K-2. Recruitment Permission from Facebook Support Group, Kidney Transplant and Weight Loss.

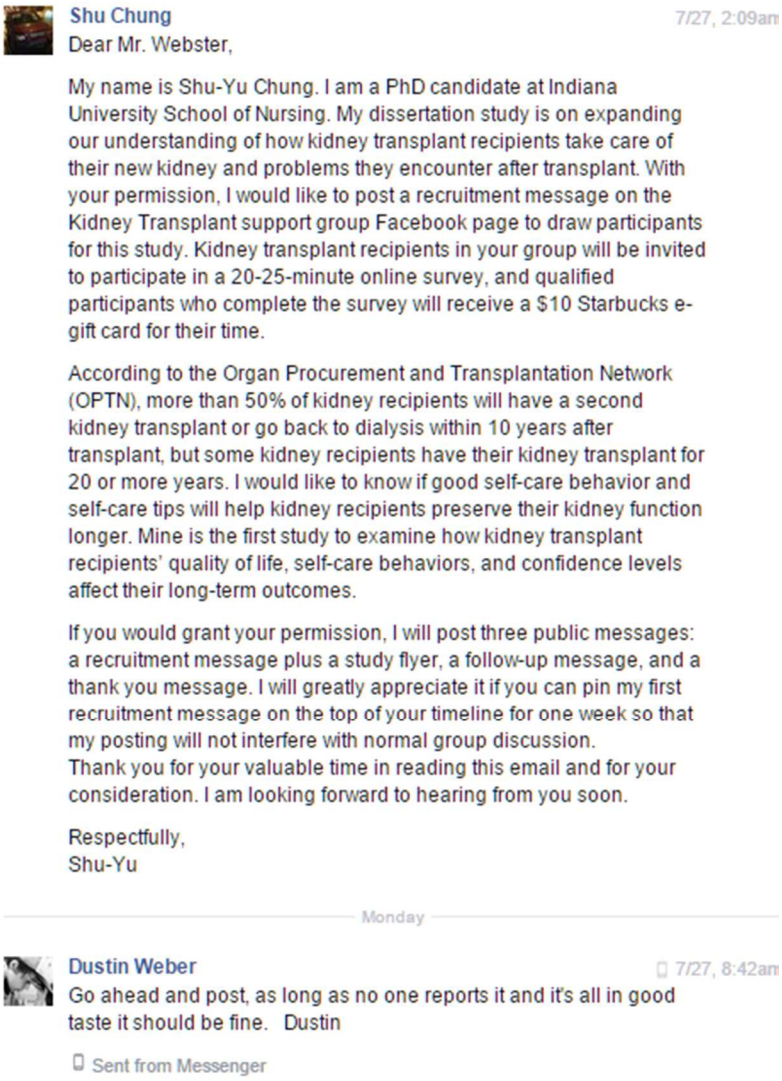

Figure K-3. Recruitment Permission from Facebook Support Group, Kidney Transplant.

APPENDIX L

FACEBOOK MESSAGES

First Facebook Public Recruitment Message

Kidney transplant recipients are needed for a study on health self-management conducted by a Ph.D. candidate at the Indiana University School of Nursing. Qualified participants who complete a 20–25-minute online survey will receive a $5 Amazon e-gift card within 5 business days. Simply click on the link below to see if you qualify for the study: https://redcap.uits.iu.edu/surveys/?s=99FN9AFYAR

This study is completely anonymous, and we will not ask for any personal identifiable information. If you are interested or want more information, please visit the Facebook study page or contact Shu-Yu Chung at @iu.edu or (812) . If you would like to see a brief summary of the study results, we hope to post them on our Facebook study page (www.facebook.KTXSM) and on the Facebook kidney transplant support group page in early July.

Second Public Recruitment Message

Thank you so much to all who have participated so far in the kidney transplant self-management study! If you have completed the online survey, you should be receiving your e-gift card very soon if you haven't gotten it already. In order to accurately describe important self-care behaviors and knowledge that may help transplanted kidneys last longer, we are still looking for more participants to take the 20–25-minute online survey. Please click on the link to see if you qualify for the study: https://redcap.uits.iu.edu/surveys/?s=99FN9AFYAR

If you know others who are also kidney recipients, please feel free to pass along the link above to them.

For more information, please visit the Facebook study page or contact Shu-Yu Chung at @iu.edu or (812) .

Public Thank You Message

Thank you for taking the time to complete this survey. We have collected enough survey data to help us understand if kidney recipients are confident about taking care of themselves and satisfied with their life after kidney transplant. This understanding will help us design better educational programs following transplantation.

We greatly appreciate all your help and support.

If you are interested in a summary of the study results, we hope to post them on our Facebook study page (www.facebook.KTXSM) and on the Facebook kidney transplant support group page in mid-July.

APPENDIX M

REDCAP REMINDERS

First Reminder

Subject: Share your post kidney transplant experience with a research team and get a $5 Amazon e-gift card)

Welcome to the Post Kidney Transplant Self-Management Study!

A week ago we sent you an invitation to access this full survey. If you have already completed this survey, thank you very much for your help. If you didn't have a chance to finish it yet, we hope that providing you with a survey link will make it easier for you to respond. Please simply click on the link below or copy and paste it into your web browser:

Kidney Transplant Survey

If you would like to take this survey using your iPad, please use a QR code reader to scan the QR code below:

After completing this survey, which should take about 20–25 minutes, you will receive a $5 Amazon e-gift card via email within 5 business days. If you have any questions or comments, please contact Shu-Yu Chung, RN, Ph.D. candidate at the Indiana University School of Nursing by email at @iu.edu or by phone at 812- .

Thank you in advance for your participation. We look forward to your valuable feedback!

Second Reminder

Subject: Help us understand how you take care of your new kidney (Or Help us understand your post kidney transplant self-care experience)

Welcome to the Post Kidney Transplant Self-Management Study!

Recently we sent you an email asking you to complete a survey about what you know, what you do, how confident you are, and how you feel since you began to take care of your new kidney. If you have already completed this survey, thank you very much for your help.

If you have not taken the survey yet, please take some time to do so. If you can't finish the survey in one sitting, you can save your progress and return to finish later. It should only take about 20–25 minutes to complete. Simply click on the link below to begin the survey or copy the link and paste it into your web browser.

Kidney Transplant Survey

Thank you in advance for your help. We look forward to your valuable input.
As thanks for completing this survey, you will receive a $5 Amazon e-gift card via email within 5 business days.

Third Reminder

Subject: Reminder: Help us understand how you take care of your new kidney (Or Help us understand your post kidney transplant self-care experience)

Welcome to the Post Kidney Transplant Self-Management Study!

In __month/date__(date) we contacted you asking for your help with the Post Kidney Transplant Self-Management Survey. We are writing to you again because our ability to accurately describe important self-care behaviors and knowledge that may help new transplanted kidney last longer depends on hearing from those who have not yet responded. We need your help to ensure that the results are as precise as possible.

To complete the survey questions, please click on the link below or copy and paste it into your web browser:

www.redcap.com

Your responses are completely anonymous. We will not ask for any personally identifiable information. You will receive a $5 Amazon e-gift card via email within 5 business days after completing the survey. If you have any questions or comments, please contact Shu-Yu Chung, RN, Ph.D. candidate at Indiana University School of Nursing by email at @iu.edu or by phone at 812- .

Thank you for considering our request.

Many thanks!

Final Reminder

Subject: Final Reminder! Help us understand your post kidney transplant experience and get a $5 Amazon e-gift card

We are writing to follow up on the message we sent last week asking you to take the Post Kidney Transplant Self-Management Study survey. If you would still like to participate, please click the link below and take the 20–25 minute survey:

www.redcap.com

If you cannot access the link above, please copy and paste the link into your web browser:

https://redcap.uits.iu.edu/surveys/index.php?s=DII6VDCfqz

If you would like to take this survey using your iPad or tablet, please use a QR code reader to scan the QR code below:

In appreciation for your time, respondents who complete the survey will receive a $5 Amazon e-gift card via email within 5 business days.

If you are interested in a summary of the study results, we hope to post them on our Facebook study page (www.facebook.KTXSM) and through the Facebook pages of 4 kidney transplant support groups (Transplant Support Group, Kidney Transplant and Weight Loss, and Kidney Transplant Survivors and Donors, and Kidney Transplants) in early July. We appreciate your help.

APPENDIX N

INCLUSION SCREENING QUESTIONS

1. Are you aged 18 years old or older?

   O Yes

   O No (Will be excluded from the study)

2. Did you have more than one organ transplant?

   O Yes (Will be excluded from the study)

   O No

3. Is your transplanted kidney (allograft) still functioning?

   O Yes

   O No (Will be excluded from the study)

4. Are you receiving post-transplant follow-up care in the United States?

   O Yes

   O No (Will be excluded from the study)

APPENDIX O

INSTITUTIONAL REVIEW BOARD APPROVAL

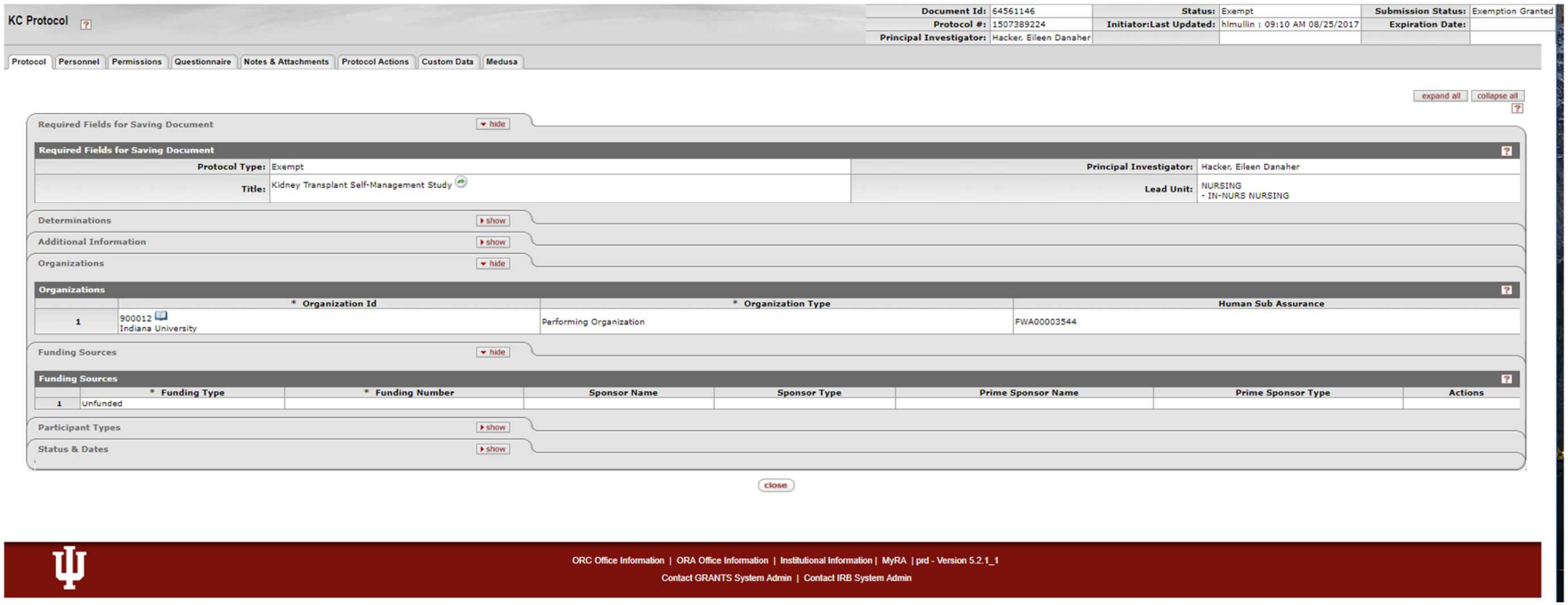

Figure O-1. Institutional Review Board Approval.

APPENDIX P

SURVEY 1: KIDNEY TRANSPLANT SELF-MANAGEMENT SCALE

Please mark the number that corresponds with your level of agreement/disagreement

Questions	Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5
1. I take my antirejection pills as instructed by my transplant doctor.					
2. I call my transplant team if my antirejection pills make me sick.					
3. I do not change the number of antirejection pills, even when my kidney is working well.					
4. I use a method, like a pillbox or reminder, to remind me to take my antirejection pills.					
5. I tell my transplant doctor about problems and concerns with my antirejection pills.					
6. If another doctor other than my transplant doctor adds a new medication, I will call my transplant doctor to see if it is safe to take.					
7. I avoid taking nonsteroidal anti-inflammatory drugs (NSAIDS) like Ibuprofen, Naproxen, or Motrin.					
8. I avoid high-calorie foods such as sweets and fried foods most of the time.					
9. I eat low-fat food such as chicken, low-fat dairy products, lean meats, poultry or fish most of the time.					
10. I watch how much sodium (salt) I eat.					
11. I read food labels most of the time.					
12. I exercise for at least 30 minutes 5 times per week.					
13. I limit alcoholic drinks to no more than one drink per day.					
14. I take my blood pressure as instructed by my doctor.					
15. I check my feet or ankles for swelling as instructed by my doctor.					
16. I call my transplant team if I gain more than 4 pounds in one day.					
17. I call my transplant doctor if I urinate (pee) less than usual.					
18. I keep almost every appointment with my transplant doctor.					
19. I keep my blood (lab) test appointments.					
20. I call my transplant doctor when I have symptoms of an infection like fever, flu-like symptoms, pain on urinating, or cough.					
21. I take my temperature as instructed by my doctor.					
22. I drink at least eight 8-ounce glasses of water (2 liters) every day.					

Table continues

23. I avoid close contact with people who are sick.					
24. I wash my hands with soap and water after using the bathroom.					
25. I wash my hands with soap and water before meals.					
26. I use sunscreen when outdoors.					
27. I wear a hat to protect my skin when outdoors.					
28. I self-examine my skin and lips at least once every month.					
29. I call my doctor if there is a suspicious lesion on my lips or skin.					

APPENDIX Q

13-ITEM PATIENT ACTIVATION MEASURE

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by circling your answer. Your answers should be what is true for you and not just what you think others want you to say.

If the statement does not apply to you, circle N/A.

1.	When all is said and done, I am the person who is responsible for taking care of my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
2.	Taking an active role in my own health care is the most important thing that affects my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
3.	I am confident I can help prevent or reduce problems associated with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
4.	I know what each of my prescribed medications do	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
5.	I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
6.	I am confident that I can tell a doctor concerns I have even when he or she does not ask	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
7.	I am confident that I can follow through on medical treatments I may need to do at home	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
8.	I understand my health problems and what causes them	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
9.	I know what treatments are available for my health problems	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
10.	I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
11.	I know how to prevent problems with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
12.	I am confident I can figure out solutions when new problems arise with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
13.	I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A

APPENDIX R

DATA TABLES

Table R-1

Correlation Matrix for the Initial 29-item KT-SM Scale

Items	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. I take my antirejection pills as instructed by my transplant doctor	__	0.62	0.42	0.29	0.57	0.25	0.20	0.11	0.23	0.26	0.04	-0.04	0.16	0.17
2. I call my transplant team if my antirejection pills make me sick	0.62	__	0.23	0.26	0.68	0.38	0.29	0.19	0.32	0.29	0.11	-0.03	0.19	0.14
3. I do not change the number of antirejection pills, even when my kidney is working well	0.42	0.23	__	0.06	0.26	0.34	0.20	0.02	0.08	0.09	-0.01	-0.04	0.05	0.28
4. I use a pill box or other reminder to remember to take my antirejection pills	0.29	0.26	0.06	__	0.38	0.18	0.11	0.06	0.06	0.04	0.19	0.02	0.13	0.10
5. I tell my transplant doctor about problems and concerns with my antirejection pills	0.57	0.68	0.26	0.38	__	0.60	0.27	0.15	0.22	0.37	0.12	0.08	0.27	0.17
6. If any doctor other than my transplant doctor gives me a new medication, I will call my transplant doctor to make sure it is safe to take	0.25	0.38	0.34	0.18	0.60	__	0.24	0.22	0.21	0.29	0.22	0.12	0.19	0.20
7. I avoid taking nonsteroidal anti-inflammatory drugs (NSAIDS)	0.20	0.29	0.20	0.11	0.27	0.24	__	0.12	0.26	0.21	0.14	0.16	0.25	0.29
8. I avoid eating sweets, fried foods and other high calorie foods most of the time	0.11	0.19	0.02	0.06	0.15	0.22	0.12	__	0.50	0.32	0.46	0.44	0.05	-0.05
9. I eat low fat foods like chicken, poultry, lean meats, or low-fat dairy products most of the time	0.23	0.32	0.08	0.06	0.22	0.21	0.26	0.50	__	0.53	0.32	0.28	0.12	0.14
10. I watch how much sodium (salt) I eat	0.26	0.29	0.09	0.04	0.37	0.29	0.21	0.32	0.53	__	0.36	0.27	0.31	0.28
11. I read food labels most of the time	0.04	0.11	-0.01	0.19	0.12	0.22	0.14	0.46	0.32	0.36	__	0.28	0.21	-0.03
12. I exercise at least 5 times per week	-0.04	-0.03	-0.04	0.02	0.08	0.12	0.16	0.44	0.28	0.27	0.28	__	0.04	0.02
13. I limit alcoholic drinks to no more than one drink per day	0.16	0.19	0.05	0.13	0.27	0.19	0.25	0.05	0.12	0.31	0.21	0.04	__	0.17
14. I take my blood pressure medication as instructed by my doctor	0.17	0.14	0.28	0.10	0.17	0.20	0.29	-0.05	0.14	0.28	-0.03	0.02	0.17	__

Table R-1

Correlation Matrix for the Initial 29-item KT-SM Scale (continued)

Items	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29
1. I take my antirejection pills as instructed by my transplant doctor	0.25	0.22	0.23	0.19	0.27	0.10	0.29	0.19	0.18	0.50	0.28	0.03	0.11	0.21	0.19
2. I call my transplant team if my antirejection pills make me sick	0.30	0.36	0.34	0.14	0.26	0.30	0.34	0.18	0.20	0.35	0.26	0.02	0.08	0.26	0.18
3. I do not change the number of antirejection pills,	0.12	0.25	0.16	0.22	0.20	0.13	0.13	0.20	0.07	0.35	0.18	0.01	0.04	0.16	0.24
4. I use a pill box or other reminder to remember to take my pills	0.26	0.20	0.21	0.16	0.19	0.10	0.20	0.15	0.18	0.13	0.06	0.13	0.08	0.10	0.18
5. I tell my transplant doctor about problems and concerns with my antirejection pills	0.27	0.39	0.38	0.34	0.27	0.39	0.28	0.13	0.22	0.37	0.34	0.10	0.10	0.29	0.20
6. If any doctor other than my transplant doctor gives me a new medication, I will call my transplant doctor to make sure it is safe to take	0.21	0.36	0.28	0.31	0.18	0.43	0.15	0.30	0.17	0.29	0.33	0.29	0.19	0.23	0.17
7. I avoid taking nonsteroidal anti-inflammatory drugs (NSAIDS)	0.17	0.19	0.09	0.28	0.33	0.12	0.09	0.08	0.13	0.35	0.19	0.20	0.12	0.33	0.26
8. I avoid high calorie foods most of the time	0.06	0.26	0.31	0.10	0.09	0.31	0.36	0.31	0.29	0.04	0.26	0.31	0.24	0.34	0.35
9. I eat low fat foods most of the time	0.13	0.26	0.28	0.15	0.29	0.25	0.41	0.28	0.23	0.33	0.37	0.33	0.06	0.44	0.31
10. I watch how much salt I eat	0.21	0.36	0.34	0.13	0.18	0.30	0.21	0.17	0.21	0.27	0.33	0.23	0.11	0.35	0.22
11. I read food labels most of the time	0.16	0.33	0.24	0.13	0.01	0.25	0.18	0.22	0.16	0.04	0.20	0.31	0.14	0.29	0.27
12. I exercise at least 150 minutes per week	-0.03	0.21	0.07	0.19	0.15	0.17	0.19	0.26	0.20	0.05	0.14	0.29	0.35	0.32	0.31
13. I limit alcoholic drinks to no more than one drink per day	0.21	0.23	0.25	0.24	0.15	0.46	0.15	0.10	0.20	0.21	0.32	-0.04	-0.04	0.12	0.19
14. I take my blood pressure medication as instructed	0.30	0.20	0.06	0.21	0.18	0.17	0.13	0.15	0.10	0.28	0.24	0.06	0.01	0.13	0.07

Table R-1

Correlation Matrix for the Initial 29-item KT-SM Scale (continued)

Items	1	2	3	4	5	6	7	8	9	10	11	12	13	14
15. I look at my feet and ankles to check for swelling as instructed	0.25	0.30	0.12	0.26	0.27	0.21	0.17	0.06	0.13	0.21	0.16	-0.03	0.21	0.30
16. I call my transplant team if I gain more than 3 pounds in one day	0.22	0.36	0.25	0.20	0.39	0.36	0.19	0.26	0.26	0.36	0.33	0.21	0.23	0.20
17. I call my transplant doctor if I pee less than usual	0.23	0.34	0.16	0.21	0.38	0.28	0.09	0.31	0.28	0.34	0.24	0.07	0.25	0.06
18. I keep every appointment with my transplant doctor	0.19	0.14	0.22	0.16	0.34	0.31	0.28	0.10	0.15	0.13	0.13	0.19	0.24	0.21
19. I keep my blood test appointments	0.27	0.26	0.20	0.19	0.27	0.18	0.33	0.09	0.29	0.18	0.01	0.15	0.15	0.18
20. I call my transplant doctor when I have signs of an infection	0.10	0.30	0.13	0.10	0.39	0.43	0.12	0.31	0.25	0.30	0.25	0.17	0.46	0.17
21. I take my temperature as instructed by my doctor	0.29	0.34	0.13	0.20	0.28	0.15	0.09	0.36	0.41	0.21	0.18	0.19	0.15	0.13
22. I drink at least eight 8-ounce glasses of water every day	0.19	0.18	0.20	0.15	0.13	0.30	0.08	0.31	0.28	0.17	0.22	0.26	0.10	0.15
23. I avoid close contact with people who are sick	0.18	0.20	0.07	0.18	0.22	0.17	0.13	0.29	0.23	0.21	0.16	0.20	0.20	0.10
24. I wash my hands after using the bathroom	0.50	0.35	0.35	0.13	0.37	0.29	0.35	0.04	0.33	0.27	0.04	0.05	0.21	0.28
25. I wash my hands before meals	0.28	0.26	0.18	0.06	0.34	0.33	0.19	0.26	0.37	0.33	0.20	0.14	0.32	0.24
26. I use sunscreen when outdoors	0.03	0.02	0.01	0.13	0.10	0.29	0.20	0.31	0.33	0.23	0.31	0.29	-0.04	0.06
27. I wear a hat to protect my skin when I am outside	0.11	0.08	0.04	0.08	0.10	0.19	0.12	0.24	0.06	0.11	0.14	0.35	-0.04	0.01
28. I examine my skin and lips once a month	0.21	0.26	0.16	0.10	0.29	0.23	0.33	0.34	0.44	0.35	0.29	0.32	0.12	0.13
29. I call my doctor if there is a suspicious lesion on my skin	0.19	0.18	0.24	0.18	0.20	0.17	0.26	0.35	0.31	0.22	0.27	0.31	0.19	0.07

Table R-1

Correlation Matrix for the Initial 29-item KT-SM Scale (continued)

Items	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29
15. I look at my feet and ankles to check for swelling as instructed	__	0.36	0.22	0.17	0.20	0.20	0.32	0.15	0.31	0.30	0.25	0.12	0.06	0.18	0.10
16. I call my transplant team if I gain more than 3 pounds in one day	0.36	__	0.54	0.24	0.22	0.41	0.50	0.15	0.20	0.17	0.29	0.21	0.20	0.40	0.36
17. I call my transplant doctor if I pee less than usual	0.22	0.54	__	0.02	0.05	0.49	0.40	0.11	0.21	0.10	0.33	0.17	0.13	0.24	0.28
18. I keep every appointment with my transplant doctor	0.17	0.24	0.02	__	0.63	0.24	0.23	0.32	0.29	0.47	0.21	0.25	0.25	0.31	0.40
19. I keep my blood test appointments	0.20	0.22	0.05	0.63	__	0.14	0.35	0.27	0.31	0.56	0.17	0.17	0.24	0.35	0.36
20. I call my transplant doctor when I have signs of an infection	0.20	0.41	0.49	0.24	0.14	__	0.42	0.25	0.39	0.14	0.48	0.17	0.04	0.27	0.35
21. I take my temperature as instructed by my doctor	0.32	0.50	0.40	0.23	0.35	0.42	1.00	0.29	0.42	0.27	0.35	0.29	0.20	0.39	0.45
22. I drink at least eight 8-ounce glasses of water every day	0.15	0.15	0.11	0.32	0.27	0.25	0.29	__	0.19	0.30	0.28	0.32	0.15	0.33	0.36
23. I avoid close contact with people who are sick	0.31	0.20	0.21	0.29	0.31	0.39	0.42	0.19	__	0.18	0.38	0.24	0.27	0.30	0.35
24. I wash my hands after using the bathroom	0.30	0.17	0.10	0.47	0.56	0.14	0.27	0.30	0.18	__	0.43	0.19	0.12	0.28	0.24
25. I wash my hands before meals	0.25	0.29	0.33	0.21	0.17	0.48	0.35	0.28	0.38	0.43	__	0.32	0.14	0.33	0.28
26. I use sunscreen when outdoors	0.12	0.21	0.17	0.25	0.17	0.17	0.29	0.32	0.24	0.19	0.32	__	0.40	0.41	0.38
27. I wear a hat to protect my skin when I am outside	0.06	0.20	0.13	0.25	0.24	0.04	0.20	0.15	0.27	0.12	0.14	0.40	__	0.29	0.27
28. I examine my skin and lips once a month	0.18	0.40	0.24	0.31	0.35	0.27	0.39	0.33	0.30	0.28	0.33	0.41	0.29	__	0.63
29. I call my doctor if there is a suspicious lesion on my skin	0.10	0.36	0.28	0.40	0.36	0.35	0.45	0.36	0.35	0.24	0.28	0.38	0.27	0.63	__

Table R-2

Correlation Matrix for the Reduced 16-item KT-SM Scale

Item	1	2	5	8	9	10	11	12	16	17	18	19	20	26	28	29
1. I take my antirejection pills as instructed by my transplant doctor	1.00	0.62	.57	.11	.23	.04	-.04	.16	.22	.23	.19	.27	.10	.03	.21	.19
2. I call my transplant team if my antirejection pills make me sick	.62	1.00	.68	.19	.32	.11	-.03	.19	.36	.34	.14	.26	.30	.02	.26	.18
5. I tell my transplant doctor about problems and concerns with my antirejection pills	.57	.68	1.00	.15	.22	.12	.08	.27	.39	.38	.34	.27	.39	.10	.29	.20
8. I avoid eating sweets, fried foods and other high calorie foods most of the time	.11	.19	.15	1.00	.50	.46	.44	.05	.26	.31	.10	.09	.31	.31	.34	.35
9. I eat low fat foods like chicken, poultry, lean meats, or low-fat dairy products most of the time.	.23	.32	.22	.50	1.00	.32	.28	.12	.26	.28	.15	.29	.25	.33	.44	.31
10. I read food labels most of the time	.04	.11	.12	.46	.32	1.00	.28	.21	.33	.24	.13	.01	.25	.31	.29	.27
11. I exercise at least 5 times per week	-.04	-.03	.08	.44	.28	.28	1.00	.04	.21	.07	.19	.15	.17	.29	.32	.31
12. I limit alcoholic drinks to no more than one drink per day	.16	.19	.27	.05	.12	.21	.04	1.00	.23	.25	.24	.15	.46	-.04	.12	.19
16. I call my transplant team if I gain more than 3 pounds in one day	.22	.36	.39	.26	.26	.33	.21	.23	1.00	.54	.24	.22	.41	.21	.40	.36
17. I call my transplant doctor if I urinate (pee) less than usual	.23	.34	.38	.31	.28	.24	.07	.25	.54	1.00	.02	.05	.49	.17	.24	.28
18. I keep every appointment with my transplant doctor	.19	.14	.34	.10	.15	.13	.19	.24	.24	.02	1.00	.63	.24	.25	.31	.40
19. I keep my blood (lab) test appointments	.27	.26	.27	.09	.29	.01	.15	.15	.22	.05	.63	1.00	.14	.17	.35	.36
20. I call my transplant doctor when I have signs of an infection like fever, flu-like symptoms	.10	.30	.39	.31	.25	.25	.17	.46	.41	.49	.24	.14	1.00	.17	.27	.35
26. I use sunscreen when outdoors.	.03	.02	.10	.31	.33	.31	.29	-.04	.21	.17	.25	.17	.17	1.00	.41	.38
28. I examine (look at carefully) my skin and lips at least once a month	.21	.26	.29	.34	.44	.29	.32	.12	.40	.24	.31	.35	.27	.41	1.00	.63
29. I call my transplant doctor if there is a change or suspicious lesion on my lips or skin	.19	.18	.20	.35	.31	.27	.31	.19	.36	.28	.40	.36	.35	.38	.63	1.00

Note. Determinant = .002.

Table R-3

Reproduced Correlation Matrix for the Reduced 16-item KT-SM Scale (5-Factor Solution)

Item		1	2	5	8	9	10	11	12	16	17	18	19	20	26	28	29
1.	I take my antirejection pills as instructed by my transplant doctor	.554[a]	.63	.55	.10	.23	.03	-.02	.12	.24	.22	.19	.28	.14	.03	.22	.15
2.	I call my transplant team if my antirejection pills make me sick	.63	.768[a]	.67	.19	.30	.10	-.01	.21	.35	.38	.15	.25	.28	.03	.25	.18
5.	I tell my transplant doctor about problems and concerns with my antirejection pills	.55	.67	.640[a]	.16	.27	.12	.03	.29	.39	.38	.31	.32	.37	.06	.27	.24
8.	I avoid eating sweets, fried foods and other high calorie foods most of the time	.10	.19	.16	.764[a]	.50	.46	.42	.08	.28	.28	.09	.09	.29	.35	.35	.32
9.	I eat low fat foods like chicken, poultry, lean meats, or low-fat dairy products most of the time.	.23	.30	.27	.50	.417[a]	.31	.30	.08	.29	.25	.19	.22	.23	.30	.42	.35
10.	I read food labels most of the time	.03	.10	.12	.46	.31	.331[a]	.28	.14	.27	.27	.11	.08	.31	.26	.29	.29
11.	I exercise at least 5 times per week	-.02	-.01	.03	.42	.30	.28	.314[a]	.05	.18	.12	.21	.16	.17	.29	.32	.31
12.	I limit alcoholic drinks to no more than one drink per day	.12	.21	.29	.08	.08	.14	.05	.317[a]	.28	.29	.26	.14	.41	.03	.09	.17
16.	I call my transplant team if I gain more than 3 pounds in one day	.24	.35	.39	.28	.29	.27	.18	.28	.448[a]	.45	.21	.19	.46	.22	.40	.39
17.	I call my transplant doctor if I urinate (pee) less than usual	.22	.38	.38	.28	.25	.27	.12	.29	.45	.517[a]	.01	.03	.49	.14	.29	.28

Table continues

18.	I keep every appointment with my transplant doctor	.19	.15	.31	.09	.19	.11	.21	.26	.21	.01	.863[a]	.62	.26	.22	.33	.40
19.	I keep my blood (lab) test appointments	.28	.25	.32	.09	.22	.08	.16	.14	.19	.03	.62	.514[a]	.14	.20	.36	.36
20.	I call my transplant doctor when I have signs of an infection like fever, flu-like symptoms	.14	.28	.37	.29	.23	.31	.17	.41	.46	.49	.26	.14	.607[a]	.16	.26	.32
26.	I use sunscreen when outdoors.	.03	.03	.06	.35	.30	.26	.29	.03	.22	.14	.22	.20	.16	.325[a]	.43	.38
28.	I examine (look at carefully) my skin and lips at least once a month	.22	.25	.27	.35	.42	.29	.32	.09	.40	.29	.33	.36	.26	.43	.704[a]	.60
29.	I call my transplant doctor if there is a change or suspicious lesion on my lips or skin	.15	.18	.24	.32	.35	.29	.31	.17	.39	.28	.40	.36	.32	.38	.60	.552[a]

Note. [a]Reproduced communalities.

Table R-4

Residual Correlation Matrix for the Reduced 16-item KT-SM Scale (5-Factor Solution)

Item		1	2	5	8	9	10	11	12	16	17	18	19	20	26	28	29
1.	I take my antirejection pills as instructed by my transplant doctor		-.02	.03	.01	-.01	.01	-.01	.04	-.02	.00	-.01	-.01	-.04	.00	-.01	.04
2.	I call my transplant team if my antirejection pills make me sick	-.02		.01	.00	.02	.01	-.02	-.01	.01	-.03	-.01	.01	.02	-.02	.01	.01
5.	I tell my transplant doctor about problems and concerns with my antirejection pills	.03	.01		-.01	-.05	-.01	.05	-.02	.01	.00	.03	-.05	.02	.03	.02	-.04
8.	I avoid eating sweets, fried foods and other high calorie foods most of the time	.01	.00	-.01		.00	.00	.01	-.04	-.02	.02	.01	.00	.02	-.04	-.01	.03
9.	I eat low fat foods like chicken, poultry, lean meats, or low-fat dairy products most of the time.	-.01	.02	-.05	.00		.00	-.02	.04	-.04	.02	-.04	.07	.02	.02	.02	-.05
10.	I read food labels most of the time	.01	.01	-.01	.00	.00		-.01	.07	.06	-.04	.02	-.06	-.06	.05	.00	-.02
11.	I exercise at least 5 times per week	-.01	-.02	.05	.01	-.02	-.01		-.01	.04	-.05	-.02	.00	.00	.00	.01	.00
12.	I limit alcoholic drinks to no more than one drink per day	.04	-.01	-.02	-.04	.04	.07	-.01		-.05	-.04	-.02	.01	.05	-.07	.03	.02
16.	I call my transplant team if I gain more than 3 pounds in one day	-.02	.01	.01	-.02	-.04	.06	.04	-.05		.09	.03	.02	-.05	-.01	-.01	-.03
17.	I call my transplant doctor if I urinate (pee) less than usual	.00	-.03	.00	.02	.02	-.04	-.05	-.04	.09		.00	.02	-.01	.03	-.05	.00
18.	I keep every appointment with my transplant doctor	-.01	-.01	.03	.01	-.04	.02	-.02	-.02	.03	.00		.01	-.02	.04	-.02	-.01
19.	I keep my blood (lab) test appointments	-.01	.01	-.05	.00	.07	-.06	.00	.01	.02	.02	.01		.00	-.04	-.01	.01
20.	I call my transplant doctor when I have signs of an infection like fever, flu-like symptoms	-.04	.02	.02	.02	.02	-.06	.00	.05	-.05	-.01	-.02	.00		.01	.01	.03
26.	I use sunscreen when outdoors.	.00	-.02	.03	-.04	.02	.05	.00	-.07	-.01	.03	.04	-.04	.01		-.01	.00
28.	I examine (look at carefully) my skin and lips at least once a month	-.01	.01	.02	-.01	.02	.00	.01	.03	-.01	-.05	-.02	-.01	.01	-.01		.03
29.	I call my transplant doctor if there is a change or suspicious lesion on my lips or skin	.04	.01	-.04	.03	-.05	-.02	.00	.02	-.03	.00	-.01	.01	.03	.00	.03	

Note. There are 9 (7.0%) nonredundant residuals with absolute values greater than 0.05.

APPENDIX S

FACEBOOK ADVERTISEMENT MESSAGE

Figure S-1. Paid Facebook Recruiting Ad.

APPENDIX T

TARGETED KT FACEBOOK RECRUITING MESSAGE

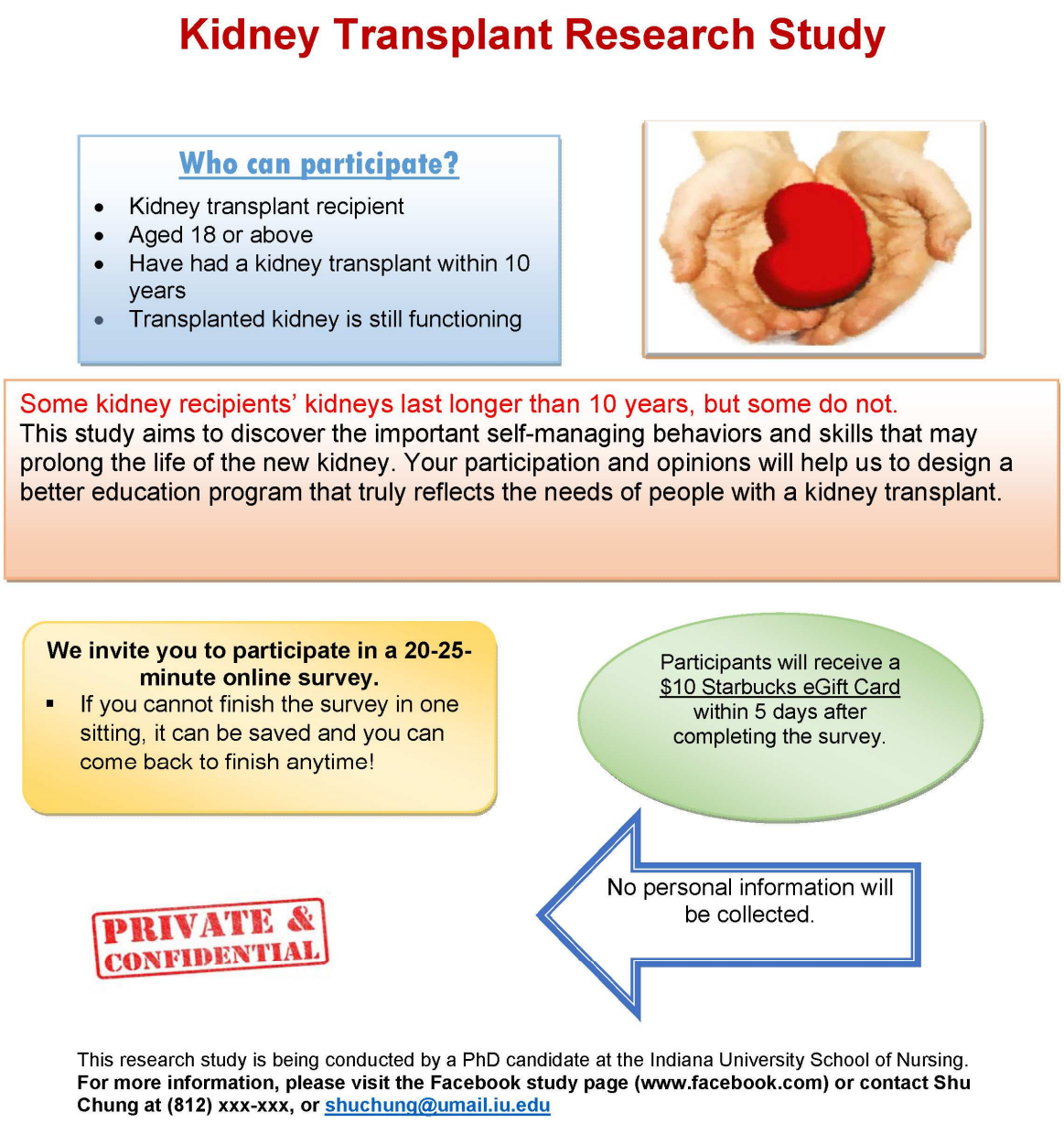

Figure T-1. Targeted KT Facebook Recruiting Message.

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Education

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Indiana State University, Terre Haute, IN	MSN	2008
National Taipei College of Nursing, Taipei, Taiwan	BSN	1998

Professional Licensure and Certifications

Registered Nurse (Indiana)	2006 to present
Basic Life Support (BLS) Certificate for Healthcare Profiders	2018 to 2020
Registered Nurse (Taiwan)	
Severe Acute Respiratory Syndrome (SARS) Nursing Care Training	May 2003
Post Organ Transplantation Care Training Course	May 2002
Advanced Cardiac Life Support Training (Taiwan Heart Association & American Heart Association)	May 1999 to 2009
Advanced Critical Care Training Course	August to November 1999

Professional Memberships

Sigma Theta Tau International (STTI), Alpha Chapter	2013 to present
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Clinical Practice

Post-Op Renal Transplant Care Unit Transplant Unit Registered Nurse St. Vincent Hospital, Indianapolis, IN USA	2008 to 2009
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