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Determinants of Active Pursuit of Kidney Donation: Applying the Theory of Motivated Information Management

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Determinants of Active Pursuit of Kidney Donation: Applying the Theory of Motivated

Information Management

An Exploratory Analysis

A thesis submitted in partial fulfillment of the requirements for the

degree of Master of Science at Virginia Commonwealth University.

by

Stacy M. West, BA, Temple University 2008

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Abstract

DETERMINANTS OF ACTIVE PURSUIT OF KIDNEY DONATION: APPLYING THE THEORY OF MOTIVATED INFORMATION MANAGEMENT, AN EXPLORATORY ANALYSIS

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End stage renal disease (ESRD) is a growing epidemic impacting the United States. While the

optimal treatment for ESRD is renal replacement, barriers exist making this treatment difficult

and sometimes impossible for patients to pursue. One potential solution to existing barriers is to

encourage patients to actively seek living donors. This is an inherently communicative and

social process. The Theory of Motivated Information Management (TMIM) offers a framework

for understanding factors that contribute to patients' conversations about transplantation with

their social networks. It is also possible that Patient Empowerment can add to this model, and

inform future patient education.

Specific variables related to the TMIM and Patient Empowerment are analyzed in bivariate and

logistic regression analyses.

Variables that were significant in bivariate analysis did not rise to the level of significance when included in a full logistic regression analysis. Study results and outcomes suggest that further research is warranted.

Background and Significance

End Stage Renal Disease in the United States

End Stage Renal Disease (ESRD) is the total and permanent loss of kidney function; requiring patients receive renal replacement therapy for survival. In the year 2015, ESRD was estimated to affect approximately 661,648 in the United States alone ("USRDS," n.d.). Research on the progression and development of Chronic Kidney Disease (CKD) in the US projects an increase in prevalence from the present rate of 13.2% to 14.4% and 16.7% in 2020 and 2030, respectively, for adults aged 30 and older (Hoerger et al., 2015). Furthermore, both incidence and prevalence of CKD progression to ESRD is projected to increase globally by 2020, in part because increased access to care ensures patient survival through the disease progression from CKD to ESRD (Hoerger et al., 2015). It would not be an exaggeration to say that kidney disease is a growing epidemic, the cost of which is absolutely staggering both its in economic and human toll. ESRD is the only disease that qualifies an individual to receive Medicare benefits regardless of their qualifying age, and as such all citizens share much of the burden of the cost of kidney disease.

Treatment options for patients with ESRD include medical management of the disease, dialysis or the mechanical filtration of blood or transplantation. Transplantation is considered a more cost effective treatment option, as long run costs associated with this means of treatment are one third the cost of maintaining long term dialysis care (Eggars, 1988). Health outcomes are also significantly more favorable, with the 5-year survival rate of transplanted ESRD patients exceeding that of a patient who receives long term dialysis by more than double (http://www.niddk.nih.gov/health-information/health-statistics/Pages/kidney-disease-statistics-

united-states.aspx). Patients who are ultimately treated with kidney transplantation report higher quality of life, and better overall health than those on continued hemodialysis (Fujisawa et al., 2000). Additionally, preemptive kidney transplantation, or transplantation prior to the initiation of dialysis has been shown to be the optimal means of treatment, as time on dialysis prior to transplantation has been found to be the strongest modifiable predictor of graft survival in transplanted patients (Meier-Kriesche & Kaplan, 2002). However, numerous barriers exist which may prevent a patient from gaining an active listing status, or even actively pursuing listing for transplantation.

Today, more than 100,647 people are awaiting a transplantable kidney in the United States (https://optn.transplant.hrsa.gov/). Many of these patients will continue to wait for many years, and some will ultimately lose their battle with ESRD before a suitable kidney becomes available to them. Part of the burden of seeking a transplant falls on the patient who is tasked with exploring and understanding the available treatment options. This, however, is not where the process ends. Once a patient has been deemed eligible for transplantation, the waiting begins. In 2007, the average ESRD patient remained waitlisted for 7.6 years while awaiting a cadaveric, or deceased donor kidney transplant (Hart et al., 2016). Increasing access to and the availability of kidney transplantation will impact future mortality rates for these patients, as well as expenditures related to ESRD and renal replacement therapy at the societal level.

Communication in ESRD

In understanding the factors that impact a patients' likelihood of pursuing and attaining a living or deceased donor kidney transplant, communication has been implicated as an important factor in this process. Progress along the path to transplantation is inherently communicative and social, particularly for patients interested in receiving a live donor kidney transplant. Before even

being considered as a candidate for transplantation, patients must communicate interest in transplantation with their health care team; obtain a referral and consult with a transplant center for evaluation. Discussion of transplantation with a spouse or partner, for instance, has been associated with an increased likelihood of patient-physician discussion of the topic, a necessary first step to be referred to a transplant center for evaluation and subsequent wait listing (Boulware et al., 2005). Upon listing, communication becomes important in the process of finding a living donor, with patients needing to communicate their interest in transplantation to others, ask for a potential donor to be tested, or share their need for a transplant with their community (Waterman et al., 2015).

Patient communication with others is positively associated with transplant-related outcomes in several ways. Open communication about kidney transplantation and, specifically, living kidney donation, can help families navigate the difficult decision making process in several ways: early discussion allows patients and their families to explore risks of living transplantation as well as benefits, identify potentially suitable candidates and discern the actual likelihood of living transplantation as a treatment option, and to ensure that in cases of a suitable and willing candidate, that required eligibility testing is completed in a timely manner (Boulware et al., 2013). Patient-initiated discussion of transplantation serves numerous additional purposes as well, including sharing family history, obtaining social support, and garnering the advice and opinions of others (Traino HM, West SM, Nonterah CW, St. Clair Russel J, n.d.) Although transplant-related dialogues serve several advantages, patients' reticence to hold transplant-related conversations is well documented.

Previous research indicates that the means of treatment most patients prefer is transplantation (Boulware et al., 2005; Kranenburg et al., 2007). While most patients would be

willing to accept a kidney donation if the prospective donor offered it to them, an overwhelming majority would not directly ask the potential donor to be tested (Kranenburg et al., 2007; Waterman et al., 2006). ESRD patients may feel guilty about the request, or have concerns for the future health and quality of life for the donor, or fear a negative reaction or damage to the relationship with the potential donor should they make the request (Kranenburg et al., 2007; Waterman et al., 2006). Patients may assume that if a family member or friend had an interest in donating a kidney to them, they would make the offer without prompting. However, in Kranenburgs et al study of 91 ESRD patients and their caretakers, one-third of patient caregivers indicated that they would be open to being tested as a potential donor were they asked (Kranenburg et al., 2007). Of the caregivers who were reluctant about the idea of donation, the most commonly voiced concern was fear for their own health after donation. Additionally, in a survey of 172 non-donating family and friends of ESRD patients, only 20% of respondents felt they were well informed about living donor kidney transplantation, and 33.7% indicated that they had never had a conversation with the patient about the prospect of donating. Of those who had discussed living donation, 30.7% (n=114) ultimately went on to be tested (Stothers, Gourlay, & Liu, 2005). This indicates that adequate communication about the potential risks, benefits and need for donation could potentially increase the number of patients who receive living donor transplants by allowing the patient to discuss concerns and provide information about the risks, benefits and procedures related to transplantation.

In recent years, there has been a notable increase in research examining communication as it relates to kidney disease and donation or transplantation, ranging from studies of the value of communication with physicians and family and community members, to the reasons patients may desire but not actively communicate about and pursue living transplantation. In a 2009

systematic review of the literature surrounding transplantation and dialysis decision-making in patients with CKD, Murray et al found that "studies typically focused on healthcare professional's provision of information about the decision rather than identifying decisional conflict and supporting patients in decision-making"(Murray et al., 2009). Thus, while communication has been implicated as a crucial piece in the medical decision making process, particularly as it relates to ESRD and transplantation, no attempt has been made to understand ESRD patients' communication (or lack thereof) through the lens of information seeking and management.

Theory of Motivated Information Management

The Theory of Motivated Information Management (TMIM) serves as a unifying social psychological theoretical framework for understanding the information management process (W. A. Afifi & Weiner, 2004). Often cited in medical sociological analyses of health behaviors, this theoretical perspective is firmly rooted in post-positivist thinking. TMIM is undergirded by and borrows from a number of earlier theoretical models that attempt to explain and predict the experience of uncertainty and the ways in which humans attempt to address, or sometimes embrace, that uncertainty. Specifically, TMIM grew out of Uncertainty Management Theory (Brashers, Goldsmith, & Hsteh, 2002) and Problematic Integration Theory (Babrow, 2001), and leans heavily on Efficacy Theory (Bandura, 1998). Additionally, the TMIM adopts the perspective of human cognition as put forth by bounded rationality theory, which assumed that, while humans are generally rational beings, the degree of rationality is subject to limitations and biases. As such, TMIM necessitates "an implicit belief in the limited rationality of the information-management process" (W. A. Afifi & Weiner, 2004; pg 171). TMIM is distinct from preceding theories on information management, however, in that it proposes a comprehensive

model of understanding information seeking behaviors which explicitly incorporates a detailed

and specific role for efficacy measures, and, therefore is the only interpersonal uncertainty

framework to account for both the assessments made by the information seeking, and the

decision making of the information provider on the process in its entirety (W. A. Afifi & Weiner,

2004). Although admittedly, the role of the provider remains largely under-studied at this time

(W. A. Afifi et al., 2006).

The theory of motivated information management proposes a three-phase process,

consisting of interpretation, evaluation, and decision-making phases. The model represents a

repetitive and iterative process of decision-making regarding information seeking behavior,

whereby, "assessments in the evaluation phase affect choices made in the decision phase, which

in turn influence future evaluations." (W. A. Afifi & Weiner, 2004, pg 171). Another unique

characteristic of TMIM is the explicit recognition that decision making regarding information

seeking behaviors is contextually situated and cannot be separated from the specific

circumstances dictating the potential emotional impact of the information discrepancy

experienced by the individual. Thus, TMIM is situated in the social realm in the context of

interpersonal information sharing about topics that are of particular importance to the

information seeker (W. A. Afifi & Weiner, 2004)

Interpretation phase

The first phase, the interpretation phase, is characterized by recognition of an

"information discrepancy", and the ensuing emotions related to that discrepancy. In its initial

formulation, TMIM identified anxiety as the ensuing emotional response to a recognized

emotional discrepancy. Greater levels of uncertainty do not necessarily translate in to higher

levels of anxiety, as TMIM recognizes that in some circumstances uncertainty may be the

preferred state, leaving the individual comfortable with the level of uncertainty or, in some situations, even desiring to increase their levels of uncertainty (Afifi & Weiner 2004). To this end, an information discrepancy for the purposes of TMIM is defined as a difference between the desired amount of information and the actual amount of information known about a given topic. Information discrepancy-related anxiety is described as the emotional equivalent to an information discrepancy, presenting a physiological response to the recognition of difference between Set Values (SV), or goals, and Actual Values (AV), or the real value of the information known to the individual (W. Afifi & Weiner, 2004; Ursin & Eriksen, 2004). While, in its initial formulation, "anxiety" was identified as the primary emotional response to an information discrepancy that motivates the actor into the next phase in the model, later iterations of the model have recognized that other emotional responses may result from an information discrepancy, ranging from positive to negative reactions (Morse et al., 2009) An emotional response to an information discrepancy is predicted to partially mediate the relationship between an uncertainty discrepancy and information seeking strategies by effecting the assessments made in the evaluation phase, with higher levels of anxiety or negative emotional responses being negatively associated with direct information seeking tactics (Morse et al., 2009).

It is worthwhile to note that TMIM does not make the assumption that all information discrepancies are likely to motivate an individual to evaluation, but rather suggests that the predictive power is associated only with areas of great concern or value to the individual. As an example, an individual may experience anxiety related to an uncertainty discrepancy when she realizes that she does not know if her partner would be willing to donate a life-saving kidney to her, but less likely to have this experience if the discrepancy is related to what her partner is planning to make for dinner. To this end, the applicability of TMIM is limited to interpersonal

communications related to a subject matter of importance to the actor in question. Furthermore, in some instances the emotional reaction is not one that motivates an individual to seek additional information, but rather promotes an acceptance of this uncertainty as preferable to "knowing" and perhaps having to face changes necessary to address the identified issues. Consider instances where a health concern presents itself, but the would-be patient determines that it is preferable to live with the uncertainty of what is causing their symptomology than it is to discover without question that they are ill. Such fear of knowing has been implicated as a barrier in HIV testing, as an example (Meiberg, Bos, Onya, & Schaalma, 2008). TMIM proposes a relative understanding of human behavior, recognizing that the factors that motivate an individual to action are varied and contextually situated and should be treated as such in this theoretical construct.

Evaluation phase

Upon experiencing an emotional reaction to an uncertainty discrepancy, individuals advance to the next phase in this process - the evaluation stage. The evaluation phase consists of two general assessments: a) Outcome assessments, or the anticipated outcome of the actor's potential information seeking behavior and b) efficacy assessments, or the degree of confidence one has in his or her ability to produce the expected outcomes in seeking this information. In articulating the distinction between the two constructs, Afifi et al (2006) explain: "outcome expectancy is an assessment of the rewards and costs that will likely result from an action, while efficacy judgments reflect whether something or someone can engage in that action." (Afifi et al, 2006; pg. 193). TMIM predicts that a higher level of anxiety or other negative emotional response to a recognized information discrepancy "will be negatively associated with positive outcome expectancies and efficacy judgments" (Fowler & Afifi, 2011, p. 512).

Outcome Assessments

TMIM explicitly recognizes three distinct outcome variables that, when combined, make up the outcome assessments construct in the evaluation process, including: *Outcome Expectancies (OE)* – the anticipated result of a specific behavior or action; *Outcome Importance (OI)*-the relative usefulness of the expected outcomes and; *Outcome probability (OP)*-the "perceived likelihood that the outcome expectancies will actually occur" (W. A. Afifi & Weiner, 2004; 176). *Outcome expectancies* (OE) are further divided in to two subparts-outcome expectancies related to results, and outcome expectancies related to the act of information seeking itself. For example, one may decide not to request living kidney donation because they anticipate rejection or anger in response to the request (result-based expectancy) or because they believe that the act of requesting donation makes them seem selfish or uncaring to their conversational partner (process-based expectancy). The combined impact of these two perceptions make up the outcome expectancy variable. *Outcome importance* (OI) recognizes that the value placed on a particular expected outcome can determine the level of effort that an individual is willing to commit to pursuing that outcome. Outcome value has been identified as being important to understanding motivation and behavior, with greater valuation of an anticipated outcome predicting behavioral intentions (Maddux, Norton, & Stoltenberg, 1986; Meece, Wigfield, & Eccles, 1990). Outcome probability relates to the perceived likelihood of an action resulting in a desired (or undesired) outcome. Afifi & Weiner, in their inclusion of this factor, recognize that "uncertainty about an issue is likely to be strongly associated with uncertainty about a specific outcome (i.e., OP)," but that the inclusion of OP in the model adds to the predictive strength of TMIM, nonetheless (W. A. Afifi & Weiner, 2004, p. 177)

Efficacy Assessments

　　Research in to the role of efficacy in behavioral decision making is promising, indicating that perceptions of ability can serve as mediators in the cognitive processes that determine whether one engages in a particular action. In Bandura's 1982 review of various research studies examining self-efficacy perceptions in relation to psycho-social processes, he concluded that, "Perceived self-efficacy predicts degree of change in diverse types of social behavior (Kazdin, 1979; Barrios, Note 4); varieties of phobic dysfunctions (Biran & Wilson, 1981; Bburque & La-douceur, 1980); stress reactions and physiological arousal (Bandura et al., in press); physical stamina (Weinberg et al., 1979; Weinberg, Yukelson, & Jackson, 1980); self-regulation of addictive behavior (Gondiotte & Liechtenstein, 1981; DiClemente, 1981); achievement strivings (Bandura & Schunk, 1981; Collins, 1982; Schunk, 1981); and career choice and development (Betz & Hackett, 1981; Hackett & Betz, 1981; Hackett, Note 5). (Bandura, 1982; pg 129). Moreover, this research indicated that perceptions of self-efficacy as opposed to actual efficacy (i.e., whether or not the behavior in question can actually be performed) were stronger predictors of behavioral outcomes. However, TMIM is the only information seeking paradigm to incorporate a well defined, specific and "explicitly recognized" role for self-efficacy assessments in predicting information seeking behaviors (Afifi et al, 2006).

　　The TMIM accounts for the impact of efficacy by recognizing the specific types of efficacy assessments that are relevant to the information-seeking decision making process. According to Afifi et al (2006), three distinct efficacy perceptions can be identified as impacting interpersonal communication: communication efficacy, coping efficacy and target efficacy. Communication efficacy as defined by TMIM is related to individuals' perceived ability to communicate effectively about the topic, and engage in a meaningful way in a specific

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information seeking behavior. Communication efficacy has been shown to predict patient communication and behavior in several health related informational settings; for example, a 2012 study of cancer patients and their partners found that communication efficacy perceptions predict both patient and patient-partner coping behaviors related to a cancer diagnosis (Checton et al., 2012). Additionally, communication efficacy has been positively associated with information seeking in the context of family health information, and sexual health information, and moderately associated with intentions to use pharmacy-based medical management plans (Carter et al,, 2012; Hovick, 2014). USE APA if more than 3 authors, et al.,)

Coping efficacy relates to individuals' ability to cope with the information and whatever consequences this new information may present. In deciding whether or not to employ a particular information seeking strategy or other behavior, the actor considers his or her own ability to include emotional and resource related abilities, and to cope with the information and/or consequences of that behavior. This might include having the emotional fortitude to withstand negative information, or the environmental resources necessary to overcome an obstacle that may otherwise inhibit one's ability to follow through with a particular strategy. Low coping efficacy can lead to higher levels of stress and anxiety relative to a particular topic, serving to paralyze rather than motivate an individual to action (Bandura, 1982). In a study of physical activity and exercise behaviors, coping efficacy emerged as the factor that "distinguishes between behavioral levels", as perceived abilities to overcome personal and environmental obstacles related to a task were strongly correlated with performance (Rodgers & Sullivan, 2001).

Target efficacy is comprised of two specific constructs - target ability and target honesty. Target ability relates to the perception of whether the target, or would be conversational partner,

has access to the information that is being sought. Target honesty captures the perceived likelihood that a conversational partner will be willing to provide that information in its entirety to the information seeker. Afifi and Weiner (2004) submit that information seekers will avoid conversational partners who are viewed as not having or having access to the desired information, or as being unlikely to provide that information honestly and completely. TMIM predicts that positive outcome assessments are positively associated with efficacy assessments. Efficacy assessments, in turn, are positively associated with the decision to seek information in a direct manner (Fowler & Afifi, 2011).

Decision phase

The information seeking strategy employed in the decision phase is ultimately reliant upon outcome and efficacy conclusions, which are drawn in the evaluation phase of the TMIM model, with greater perceptions of efficacy and more positive outcome expectations being associated with information seeking strategies. However, information seeking is not the only potential direction, nor is direct information seeking the only information seeking strategy likely to result from this cognitive process. Rather, less direct tactics for pursuing information are frequently employed by individuals who determine to obtain information from others. In studies of patient-physician interactions, patients were often found to employ more indirect methods of information seeking, such as asking indirect questions or talking around the subject, even though such tactics resulted in less information being provided (Brashers et al., 2002).

In a study on information seeking related to Sexually Transmitted Infection (STI) status, individuals with lower communication and target efficacy were more likely to engage in indirect information seeking strategies when information was ultimately sought (Dillow & Labelle, 2014). Additionally, research on information seeking behaviors indicates that information

avoidance sometimes emerges as the preferred method for addressing an information

discrepancy (Brashers et al., 2002), while still other assessments may lead the individual to

reassess the issue altogether. Thus, Afifi and Weiner identify three general outcomes in TMIM's

Decision phase: 1) seeking relevant information, 2) avoiding relevant information or 3) engaging

in a cognitive reappraisal of the issue in question (Afifi and Weiner, 2004). While direct

information seeking tactics are often viewed as the primary means of managing uncertainty,

information avoidance has emerged as a tactic sometimes employed, and particularly in

situations related to healthcare (W. A. Afifi & Weiner, 2004; Dillow & Labelle, 2014; Sweeny,

et al,, 2010).

According to Sweeny et al (2010), information avoidance activities can fall into one of

two broad categories similar to information seeking behaviors, avoidance may entail active

avoidance or passive avoidance: "That is, information avoidance can be active (e.g., by asking

someone not to reveal information) or passive (e.g., by failing to ask someone a question that

would reveal the information)." (pg. 341). *Cognitive Reappraisal* emerges as another alternative

to information seeking strategies, and involves "making psychological adjustments that change

the mechanism that activated the original need for information." (Afifi and Weiner 2004; pg.,

183). This final strategy eliminates anxiety related to the perceived information discrepancy,

leading the actor to accept the information discrepancy by either reassessing the importance of

the issue, the amount of information actually desired, or by re-characterizing the meaning and

function of uncertainty altogether.

In the context of ESRD patients' discussions about kidney transplantation, the TMIM

provides a framework for understanding the cognitive mechanisms underlying and ultimately

determining patients' communication about kidney transplantation and living donation. Research

on the applicability of TMIM to organ donation has thus far been limited to decisions and information seeking related to deceased organ donation. However, this research and other applications of TMIM in the healthcare setting have indicated that the model is a good fit for predicting information seeking behaviors in the context of transplantation. It is here that the TMIM becomes explicitly social. Understanding what drives an individual to seek information about family, friends', peers' and other associates' perceptions of living and deceased donor kidney transplantation and living donation specifically, may lead to the identification of modifiable factors that can be manipulated to encourage greater pursuit of this treatment modality; thus, improving the health outcomes for all patients with ESRD.

The following hypotheses are derived from the Theory of Motivated Information Management:

H1: ESRD patients will express a discrepancy in the amount of information they have regarding   others' perceptions of transplantation.

H2: A heightened negative emotional response resulting from the uncertainty discrepancy will be negatively related to positive outcome assessments and higher efficacy assessments

H3: Positive outcome expectancies will be positively related to efficacy assessments.

H4: Higher efficacy assessments are positively related to the decision to directly seek information.

Patient Empowerment

Over the last decade, the importance of patient or health empowerment has grown, particularly in relation to diabetes and self-care management (Anderson & Funnell, 2010; Kubsch & Wichowski, 1997). This interest in empowerment and its relationship with healthcare stems from previous work applying the construct to educational, organizational and social

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settings (Aujoulat, d'Hoore, & Deccache, 2007; Menon, 2002). However, there is a lack of

consensus regarding the definition and application of empowerment in the healthcare setting, as

the definition of empowerment can be broad and easily conflated with other defined variables,

such as self-efficacy (Anderson & Funnell, 2010; Gibson, 1991; Menon, 2002). One common

thread amongst various definitions of this construct, however, is the idea of control over one's

situation. This idea of control is common to theories of empowerment in communities,

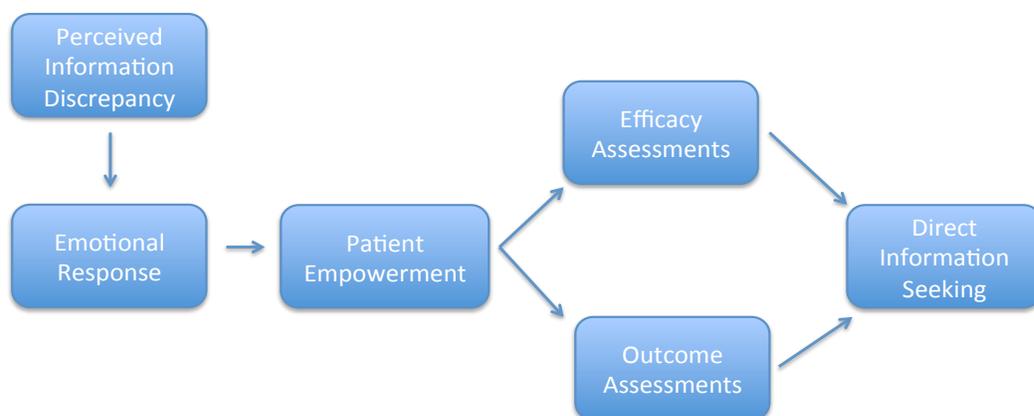education, workplace and healthcare settings.

Empowerment, however, is not derived from "decisional control" over everyday health

related activities as has previously been thought, but rather can be derived from a recognition of

"personal and socio-contextual resources" (Crawford Shearer, 2009, p. 6) such as social support

and services, and the perceived ability to engage in health promoting activities (Crawford

Shearer, 2009; Kubsch & Wichowski, 1997). Menon (2002) defines patient empowerment as "a

cognitive state characterized by perceptions of control regarding one's own health and health

care; perceptions of competence regarding one's ability to maintain good health and manage

interactions with the health care system; and internalization of health ideals and goals at the

individual and societal level" (Menon, 2002, p. 22). This definition speaks to the variable and

modifiable nature of empowerment, as perceptions of control, autonomy, and personal and social

resources can be impacted through targeted intervention.

Several studies have identified a relationship between higher degrees of patient

empowerment and a more active and involved role in self-care activities (Aujoulat et al., 2007;

Carter et al., 2012; Eyüboğlu & Schulz, 2016). Empowerment interventions generally attempt to

imbue patients with a set of psycho-social skills that have broad applicability to their everyday

lives, and not just within a healthcare setting, such as coping skills, problem recognition, goal

integration and communication skills (Aujoulat et al., 2007). It is possible that a greater sense of empowerment could be associated with a reduction in negative emotional response to an information discrepancy; thereby promoting more positive outcome expectancies and efficacy assessments and leading to a greater likelihood of information seeking behaviors.

Thus, the study's final hypothesis is derived from Patient Empowerment theory situated within the framework provided by TMIM:

H5: There will be a negative association between Patient Empowerment and anxiety related to the information discrepancy.

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┌──────────────┐
│  Perceived   │
│ Information  │
│ Discrepancy  │
└──────┬───────┘
       │
       ▼                                  ┌──────────────┐
┌──────────────┐      ┌──────────────┐    │   Efficacy   │
│  Emotional   │ ───▶ │   Patient    │ ─▶ │ Assessments  │ ─┐     ┌──────────────┐
│  Response    │      │ Empowerment  │    └──────────────┘  │     │    Direct    │
└──────────────┘      └──────┬───────┘                      ├──▶  │ Information  │
                             │            ┌──────────────┐  │     │   Seeking    │
                             └─────────▶  │   Outcome    │ ─┘     └──────────────┘
                                          │ Assessments  │
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Figure 1. TMIM and Patient Empowerment Model

Methods

Overview

      To test the predictive capabilities of the TMIM in the context of patient discussions about deceased and living kidney transplantation, secondary data collected from June 2013 to September 2015 in the conduct of a randomized controlled trial of the behavioral communication intervention, <u>Co</u>mmunicating <u>a</u>bout <u>Ch</u>oices in Transplantation (COACH) study, was obtained from the study's principal investigator (Dr. Heather Traino). As Study Coordinator for this project, I was responsible for managing all aspects of data collection, from participant recruitment and enrollment to conducting interviews and overseeing a team of interviewing research assistants.

Patient Recruitment

      Patient participants were sampled from the universe of ESRD patients waitlisted for kidney transplantation at two mid-Atlantic transplant centers. To be eligible for participation, patients must have been at least 18 years of age, English speaking, and actively listed or in the process of becoming actively listed on the national waitlist at the time of recruitment (Status 1, 2 or 7). Patients were recruited via mailed packets containing, introductory letters from the patient's transplant center and from the research team; the informed consent document; a pictorial representation of the study; and a self-addressed, postage paid, opt-out postcard that could be returned to the research team to indicate that no further contact was desired. If no opt-out card was returned, telephone contact was attempted two to three weeks after the packets were mailed to solicit questions about the study and invite participation. A total of 254 patient participants were enrolled over the course of the study.

COACH Patient Sample

Patients who completed baseline data collection (N=254) were majority male (n=131; 51.6%), with 66.9% (n=170) of the sample population identifying as African American. Most participants completed a high school education or equivalency (n=172; 67.7%) with 35.9% (n=91) having completed at least some post-high school education. At the time of the baseline interview, 85.8% (n=218) of participating patients had already started dialysis, with the majority of those (n=152; 69.7%) on some form of in-center hemodialysis. Several key measures related to the research question at hand are only addressed in the post intervention data collection phase; thus, only those participants who completed both a baseline and post intervention interview were included for analysis (N=184).

Upon enrollment, patients completed a semi-structured telephone interview lasting approximately 90 minutes. Participants were then randomized to receive either the standard educational materials provided by their respective transplant center (i.e., control condition) or the COACH intervention, which provided education on living and deceased donor kidney transplantation and instruction on how to effectively converse with others about kidney disease, the need for transplantation, and living donation (i.e., intervention condition). Follow-up interviews were completed at 1 and 3 months post-enrollment or attendance at a COACH session, depending on group assignment; participants randomized to the control condition were offered the opportunity to participate in a COACH session after their final interview. The appropriate institutional review boards approved the study and informed consent was obtained from all participants.

Measures

The purpose of the COACH program was to increase patient communication about kidney transplantation and, thus, most of this interview was focused on patients' conversations and plans for conversations about kidney disease and transplantation, as well as demographic data. The measures included in the present study are described in detail below.

TMIM Constructs. Theory of Motivated Information Management constructs, including Uncertainty Discrepancy (I wish I knew more about other peoples' thoughts and opinions about my transplant options), Anxiety related to the issue (Not knowing how others will react to transplantation makes me anxious) and issue importance (It is important to me to discuss my transplant options with others), Outcome Expectancy (There are more benefits to talking about my transplant options with other people than there are problems), Coping Efficacy (I would have no problem coping with other peoples' thoughts and opinions about my transplant options) and Target Efficacy (The people I talk with about transplantation will be honest about their opinions on the topic) were measured using 5 point Likert-type scales of agreement (1-Strongly Disagree/5-Strongly Agree) . The mid-point option of Neutral (3) was presented only if participants voiced uncertainty. Responses for TMIM constructs were recoded in to dichotomous variables for the purposes of this analysis, with Strongly Disagree, Disagree and Neutral recoded as Disagree, and Agree and Strongly Agree recoded as Agree. Data for this measure were collected in the post-intervention interview.

Communication Self-efficacy. Participants were asked to rate their self-confidence in performing specific conversational tasks on a scale of 0 to 100 (0-not at all confident/100-completely confident). The measure was developed for the COACH study in accordance with Bandura's instruction on the development of self-efficacy scales (Bandura, 2006). Data for this

measure were collected in the post-intervention interview. Individual items were summed to create a composite score, with higher values indicative of higher levels of communication self-efficacy (possible range of 0 to 1500).

Knowledge about Transplantation. 11 items from the available transplant patient resources. Individual items were assessed with a dichotomous true/false option. Data for this measure were collected in the post-intervention interview. Correct responses were summed to create a global knowledge score, with higher values reflecting greater knowledge (possible range of 0 to 11).

Perceived Ability to Hold Conversations about Transplantation. Three items assessing an individual's perception of their own ability to hold a conversation about transplantation and options related to transplantation was measured on a 7-point Likert-type scale (1-Strongly Disagree/7-Strongly Agree). Items were derived from previous research on liver transplantation, and adapted for this study (Delair et al., 2010). Data for this measure were collected in the post-intervention interview. Responses for Perceived Ability constructs were recoded in to dichotomous variables for the purposes of this analysis, with Strongly Disagree, Moderately Disagree, Somewhat Disagree and Neutral recoded as Disagree, and Somewhat Agree, Moderately Agree and Strongly Agree recoded as Agree.

Patient Empowerment. Five items assessing patient empowerment (for example, To what extent do you feel you have control over your kidney disease?) were measured on a 5 point Likert-type scale (1, none/5A lot), and were adapted from the Powerlessness Assessment Tool (PAT) for the COACH study (Kubsch & Wichowski, 1997). Data for this measure were collected in the post-intervention interview. Responses for Patent Empowerment constructs were

recoded in to dichotomous variables for the purposes of this analysis, with 1 (none) through 3 recoded as Low Patient Empowerment, and 4 and 5 recoded as High Patient Empowerment.

Transplant Conversations. Finally, whether or not the participant had held conversations about transplantation was assessed through a single dichotomous question (Have you ever had conversations with anyone about your transplant options; yes/no). While this question was asked at both baseline and in the post-interview, the post interview response was ultimately selected for inclusion in order to set parameters for the amount of time which the participant may have had for holding conversations. In the post intervention interview, this question was presented as "Since the last time we spoke, have you talked with anyone about your transplant options?". This variable was dichotomized as 0 (no conversations) and 1 (conversations had occurred).

Demographic Characteristics. Patients' sociodemographic characteristics were collected in the baseline interview. Variables assessed for inclusion in final analysis for this study include race (white, non-white), annual income ($39,999 or less; $40,000 or more) , educational attainment (Some college with no degree, or less; Associates degree or more), marital status (Married or cohabitating; not married or cohabitating), religious affiliation (Christian; non Christian), age (22 to 75) and gender (Male; Female). Previous research on communication about kidney transplantation has implicated certain socio demographic characteristics as important predictors of communication about transplantation. For example, Reese et al (2008) found that younger and female patients were more likely to discuss transplantation (Reese et al., 2008). Other research indicates that those who actively pursue a live donor transplantation through communication tend to be white and have higher degrees of education (Rodrigue et al, 2008). Because the intention of the COACH intervention was to increase and improve

communication about transplantation, group assignment (intervention or control group) was also

included in bivariate analysis.

Analysis

The variables included in this study for analysis are fully described in their recoded

format using means and standard deviations for continuous variables and frequency counts and

percentages for dichotomous variables (Tables 1, 2, 3, 4 and 5). Chi-square and t-tests were used

in simple bivariate analyses to assess associations between the independent variables and the

dependent variable (did you have transplant conversations), as well as to assess the relationship

between key independent variables as described in my hypotheses (anxiety with outcome

expectations and efficacy assessments; outcome assessments with efficacy assessments). Chi-

square tests were used to define the relationship between dichotomous variables; and continuous

independent variables were assessed against the dependent variable using t-tests. Results for all

bivariate analysis are presented in Tables 1, 2, 3, 4, 5 and 6. Histograms and scatterplots were

used to identify any potential outliers in the continuous variables, and none were found to be

significant enough to warrant removal from the final data set. Linearity of the continuous

variables with respect to the dependent variable was assessed via the Box-Tidwell (1962)

procedure. A Bonferroni correction was applied using all nineteen terms included in the final

model, resulting in statistical significance being accepted when $p < .005263$. Based on this

assessment, all continuous independent variables were found to be linearly related to the logit of

the dependent variable.. Finally, a step-wise logistic regression analysis was conducted adjusting

for those variables significant in bivariate analyses to identify predictors of patients holding

conversations about transplantation. Logistic regression was the most appropriate option for this

analysis because the outcome variables was dichotomous, with 0 indicating no conversation

about transplantation and 1 indicating at least 1 conversation about transplantation. The first step

of the analysis involved controlling for the effect of sociodemographic variables that were

significantly associated with the dependent variable, including age; race; marital status; and

income. In the second block, TMIM variables associated with the dependent variable in

bivariate analysis were added in to the model; these included two measures of issue importance;

outcome expectancy; and information discrepancy.   The third block added two measures of

Perceived Ability that met the criteria for inclusion. Three measures of Patient Empowerment

were added in at the fourth block; with Communication Confidence and Transplant Knowledge

added in the fifth and sixth blocks, respectively. Results for the final regression analyses are

presented in Table 7. All analyses were performed using IBM SPSS (version 22).

Results

Sociodemographics

Table 1 presents the sample characteristics and shows the bivariate relationship between

those who had a conversation with others about transplantation and those who did not..

Participant ages ranged from 22 to 75, and skewed towards middle aged with a mean of 52.0326.

The majority of the analytic sample were men (51.6%) and non-white (70%) with a majority

reporting an annual household income of $39,999 or less (59.2%). Just over half (51.6%) of

participants were single 60.9% reported having less than an Associates degree. Participant age,

race, marital status and income emerged as significantly correlated with the dependent variable at

$\alpha = .1$ level. Participants who were more likely to have had a conversation were slightly older,

with a mean age of 53.0305 as opposed to a mean age 49.5660 for those who reported no

conversations (p=.068). White patients were more likely to report having conversations at 81.5%

as compared to non-white patients at 66.7% (p=.050) and those with annual household income of

$40,000 or greater were also more likely to report having conversations than those with annual incomes below $39,999, at 79.5% compared to 65.1% . Participants who were married or cohabitating with a partner were significantly more likely to report having discussed their transplant options (p=.006).

Table 1. Description and Bivariate Analysis of Sociodemographic Characteristics and Transplant Conversations

	Total N (%)	No Conversations 53 (28.8)	Yes Conversations 98 (71.2)	
Sociodemographics				
Age (22-75) Mean (SD)	52.0326 (11.6801)	49.5660 (12.3592)	53.0305 (11.2898)	0.068
Sex/Gender				0.628
Male	95 (51.6)	29 (30.5)	47 (49.5)	
Female	89 (48.4)	24 (27.3)	51 (58.0)	
Race				
Non-white	126 (70.0)	42 (33.3)	84 (66.7)	0.050
White	54 (30.0)	10 (18.5)	44 (81.5)	
Marital Status				0.006
Not married/cohabitating	95 (51.6)	36 (37.9)	59 (62.1)	
Married/cohabitating	89 (48.4)	17 (19.1)	72 (80.9)	
Religion				0.411
Christian	166 (90.2)	46 (27.7)	120 (72.3)	
Other	18 (9.8)	7 (38.9)	11(61.1)	
Income				0.045
$40,000 or more	73 (40.8)	15 (20.5)	58 (79.5)	
$39,999 or less	106 (59.2)	37 (34.9)	69 (65.1)	
Education				0.407
Some college, no degree and less	112 (60.9)	35 (31.3)	77 (68.8)	
Associates degree or more	72 (39.1)	18 (25.0)	54 (75.0)	
Group Assignment				0.627
Intervention	96 (52.2)	26 (27.1)	70 (72.9)	
Control	88 (47.8)	27 (30.7)	61 (69.3)	

Notes: Source – COACH study (2012-2015). N=184. Data are described row n (%) for categorical variables and mean ±standard deviation for continuous variables. Chi-square and t-tests used to test for significance. (Fisher's exact test used for cells with counts less than 5.)

Theory of Motivated Information Management Variables

Table 2 presents the bivariate associations between all TMIM constructs with the dependent variable using chi-square test statistics. Two measures of the Issue Importance construct were significantly correlated with reported conversations, with those who agreed that discussing transplantation (p=.005) and learning others opinions on the topic (p=.001) are important to them being more likely to have reported having had conversations at the time of the post-intervention interview. One construct measuring Outcome Assessment was included in the bivariate analysis, and having a positive outcome expectation for conversations was significantly correlated with the dependent variable (p=.001). The measure assessing the construct Information Discrepancy also showed significant correlation with having conversations at the $\alpha = .1$ (p=.096), indicating that participants who report a discrepancy in the amount of information they would like to have about others opinions of their transplant options, and the amount of information they actually have are more likely to engage in conversations as an attempt to reduce that discrepancy.

Table 2. Description and Bivariate Analysis of TMIM Constructs and Transplant Conversations

	Total N (%)	No Conversations 53 (28.8)	Yes Conversations 98 (71.2)	p-value
TMIM Variables				
Agree it is important to discuss transplant options.				0.005
Yes	144 (78.3)	34 (23.6)	110 (55.2)	
No	40 (21.7)	19 (47.5)	21 (52.5)	
Agree it is important to know what others think of my transplant options.				0.001
Yes	111 (60.3)	22 (19.8)	89 (80.2)	
No	73 (39.7)	31 (42.5)	42 (57.5)	
Agree not knowing how others will react to discussions of transplant makes me anxious.				0.609
Yes	61 (33.2)	16 (26.2)	45 (73.8)	
No	123 (66.8)	37 (30.1)	86 (69.9)	
Agree there are more benefits to discussing transplant than problems.				.001
Yes	148 (80.4)	34 (23.0)	114 (77.0)	
No	36 (19.6)	19 (52.8)	17 (47.2)	
Agree the people I talk with about transplant will be honest in their opinions.				.595
Yes	164 (89.6)	46 (28.0)	118 (72.0)	
No	19 (10.4)	7 (36.8)	12 (63.2)	
Agree I wish I knew more about others' opinions on my transplant options.				0.096
Yes	107 (58.5)	25 (23.4)	82 (76.6)	
No	76 (41.5)	27 (35.5)	49 (64.5)	
Agree I would have no problem coping with others opinions about my transplant options.				1.000
Yes	171 (93.4)	49 (28.7)	122 (71.3)	
No	12 (6.6)	3 (25.0)	9 (75)	

Notes: Source – COACH study (2012-2015). N=184. Data are described row n (%) for categorical variables and mean ±standard deviation for continuous variables. Chi-square and t-tests used to test for significance. (Fisher's exact test used for cells with counts less than 5.)

Perceived Ability Variables

Results of bivariate analysis of Perceived Ability measures with the dichotomous Conversations variable are presented in Table 3. Two of the three measures of Perceived Ability that were assessed showed significant correlation with having had at least one conversation about transplantation. Participants who agree with the following statements: "I know enough about live donor kidney transplantation to have a conversation about it" and "I know enough about deceased donor kidney transplantation to hold a conversation about it" were more likely to report having conversations about their transplant options, at 74.2% and 73.9% reporting conversations as compared to those who disagreed with those statements at 54.2% and 55.6%. ($p=.053$ and $p=.066$, respectively).

Table 3. Description and Bivariate Analysis of Perceived Ability and Transplant Conversations

	Total N (%)	No Conversations 53 (28.8)	Yes Conversations 98 (71.2)	p-value
Perceived Ability				
Agree I know enough about live donor kidney transplantation to hold a conversation about it.				0.053
Yes	159 (86.9)	41 (25.8)	118 (74.2)	
No	24 (13.1)	11 (45.8)	13 (54.2)	
Agree I know enough about deceased donor kidney transplantation to hold a conversation about it.				0.066
Yes	157 (85.3)	41 (26.1)	116 (73.9)	
No	27 (14.7)	12 (44.4)	15 (55.6)	
Agree I am comfortable talking with others about my transplant options.				0.235
Yes	158 (86.3)	43 (27.2)	115 (72.8)	
No	25 (13.7)	10 (40.0)	15 (60.0)	

Notes: Source – COACH study (2012-2015). N=184. Data are described row n (%) for categorical variables and mean ±standard deviation for continuous variables. Chi-square and t-tests used to test for significance. (Fisher's exact test used for cells with counts less than 5.)

Patient Empowerment Variables

Variables assessing patient empowerment as a construct are comprised of measures related to hope (i.e.; I hope my condition will improve), and control (i.e.; I can control the course of my own healthcare), and results of bivariate analyses of these constructs are presented in Table 4. The patient empowerment scale includes of 3 measures related to control and two related to hope; all were assessed for a correlation with having had conversations about

transplant options. In bivariate analysis, two measures related to control ("I know what to expect

with my health" and "I can control the course of my own healthcare") and one construct related

to hope ("I feel transplantation can help me") were positively correlated with the dependent

variable at the $\alpha = $ .1 level. Of those who agreed with the statement "I know what to expect

with my health", 76.8% reported having conversations, while 64.7% of those who disagreed with

the statements reported having conversations.   Those who agreed that transplantation can help

them reported conversations in 73.4% of cases, while those who disagreed with the statement

reported having conversations in 46.7% of cases. Patients who agreed with the statement "I can

control the course of my own healthcare" were also significantly more likely to report having

had conversations; with 76.7% of those who agreed and 63.7% of those who disagreed reporting

having conversations.

Table 4. Description and Bivariate Analysis of Patient Empowerment Constructs and Transplant Conversations

	Total N (%)	No Conversations 53 (28.8)	Yes Conversations 98 (71.2)	p-value
Patient Empowerment				
Agree I have control over my kidney disease.				0.871
Yes	82 (44.6)	23 (28.0)	59 (72.0)	
No	102 (55.4)	30 (29.4)	72 (70.6)	
Agree I know what to expect with my health.				0.076
Yes	99 (53.8)	23 (23.2)	76 (76.8)	
No	85 (46.2)	30 (35.3)	55 (64.7)	
Agree I hope my condition will improve.				0.454
Yes	162 (88.0)	45 (27.8)	117 (72.2)	
No	22 (12.0)	8 (36.4)	14 (63.6)	
Agree I feel transplantation can help me.	169 (91.8)	45 (26.6)	124 (73.4)	0.038
Yes	15 (8.2)	8 (53.3)	7 (46.7)	
No				
Agree I can control the course of my own healthcare.	103 (56.3)	24 (23.3)	79 (76.7)	0.071
Yes	80 (43.7)	29 (36.3)	51 (63.7)	
No				

Notes: Source – COACH study (2012-2015). N=184. Data are described row n (%) for categorical variables and mean ±standard deviation for continuous variables. Chi-square and t-tests used to test for significance. (Fisher's exact test used for cells with counts less than 5.)

Communication Self Efficacy

This continuous variable was analyzed for correlation with the dependent variable using a t-test statistic. Analysis indicated that higher communication confidence was positively related to having discussed transplant options with others at the time of the post-intervention interview (p=.011). Those who reported having conversations had a mean self-efficacy score of 1196.6512

(SD 241.5115) and those who reported no conversations had a mean score of 1087.9615 (SD 296.2510). Results of this analysis are presented in table 5.

Transplant Knowledge

Knowledge about transplantation was also analyzed for correlation with the dependent variable using a t-test statistic, and was found to be significantly correlated (p=.022). Those who reported having conversation had a mean knowledge score of 7.5769 (SD 1.7647) and those who reported no conversations had a mean knowledge score of 6.8868 (SD 2.0064). Results of this analysis are presented in table 5.

Table 5. Description and Bivariate Analysis of Self-Efficacy and Transplant Knowledge, and Transplant Conversations

	Total	No Conversations	Yes Conversations	p-value
	N (%)	53 (28.8)	98 (71.2)	
Self Efficacy				
Self Efficacy Summed Score (220.0-1500.0) Mean (SD)	1165.4254 (262.2527)	1087.9615 (296.2510)	1196.6512 (241.5115)	0.011
Knowledge				
Knowledge Summed Score (1.0-11.0) Mean (SD)	7.3770 (1.8590)	6.8868 (2.0064)	7.5769 (1.7647)	0.022

Notes: Source – COACH study (2012-2015). N=184. Data are described row n (%) for categorical variables and mean ±standard deviation for continuous variables. Chi-square and t-tests used to test for significance. (Fisher's exact test used for cells with counts less than 5.)

Key Variables and Relationships

Bivariate analyses were also conducted to assess the relationship between certain independent variables, including Anxiety related to the issue and Outcome Assessment, Self Efficacy, and Patient Empowerment; and Outcome Assessment and Self Efficacy. Results for these analyses are presented in Tables 6, and 7 respectively. While there was no significant correlation between Anxiety and Outcome Assessment or Self Efficacy, there was a significant positive correlation between Anxiety and one "hope" measure in the Patient Empowerment construct, and a negative correlation with one control measure. Those patients who agreed with the statement "I have control over my kidney disease" reported low issue anxiety in 59.8% of cases while those who disagreed with this statement reported low issue anxiety in 72.5% of cases (p=.083). Patients who agreed "I hope my condition will improve" were more likely to report low issue anxiety, with 69.2% of those who agreed and 50% of those who disagreed reporting lower issue anxiety (p=.092). Outcome Assessment and Self Efficacy also showed a strong positive correlation, with those who reported more positive outcome assessments having significantly higher communication self efficacy (p=.000). Patients who reported more positive Outcome Assessments had a mean self-efficacy score of 1203.725 (SD 229.7083) while those with a more negative Outcome Assessment had a mean self-efficacy score of 999.838 (SD 326.9730).

Table 6. Relationship between Outcome Assessment, Self-Efficacy and Patient Empowerment with Anxiety Related to Transplant Conversations

	Total N (%)	Low Issue Anxiety 123 (66.8)	High Issue Anxiety 61 (33.2)	p-value
Outcome Assessment				
Agree there are more benefits to discussing transplant than problems.				1.00
Yes	148 (80.4)	99 (66.9)	49 (33.1)	
No	36 (19.6)	24 (66.7)	12 (33.3)	
Communication Self Efficacy				
Self Efficacy Summed Score (220.0-1500.0)	1165.4254 (262.2527)	1161.0579 (263.7805)	1174.233 (261.1313)	.751
Patient Empowerment				
Agree I have control over my kidney disease.				.083
Yes	82(44.6)	49 (59.8)	33 (40.2)	
No	102 (55.4)	74 (72.5)	28 (27.5)	
Agree I know what to expect with my health.				.532
Yes	99 (53.8)	64 (64.6)	35 (35.4)	
No	85 (46.2)	59 (69.4)	26 (30.6)	
Agree I hope my condition will improve.				0.092
Yes	162 (88.0)	112 (69.2)	50 (30.9)	
No	22 (12.0)	11 (50.0)	11 (50.0)	
Agree I feel transplantation can help me.				0.776
Yes	169 (91.8)	112 (66.3)	57 (33.7)	
No	15 (8.2)	11 (73.3)	4 (26.7)	
Agree I can control the course of my own healthcare.				0.638
Yes	104 (56.3)	67 (65.0)	36 (35.0)	
No	80 (43.7)	55 (68.8)	25 (31.3)	

Notes: Source – COACH study (2012-2015). N=184. Data are described row n (%). Chi-square used to test for significance.

Table 7. Relationship between Self-Efficacy and Outcome Assessments

	Total	Negative Outcome Assessment	Positive Outcome Assessment	p-value
	N (%)	36 (19.6)	148 (80.4)	
Self Efficacy Summed Score (220.0-1500.0)	1165.4254 (262.2527)	999.838 (326.9730)	1203.725 (229.7083)	.000

Notes: Source – COACH study (2012-2015). N=184. Data are described row n (%) for categorical variables and mean ±standard deviation for continuous variables T-tests used to test for significance.

Logistic Regression Results

Table 8 presents results of the Logistic Regression Model predicting the odds of having a transplant conversation by sociodemographics, theory of motivated information management constructs, perceived ability, patient empowerment, communication self efficacy and knowledge about transplantation. Only variables significant in bivariate analysis at the $\alpha = .1$ level are included in this analysis In block 1, sociodemographics variables that were significant in bivariate analysis were controlled for, however none of the sociodemographic variables were significant in this adjusted model.

The second model controlled for TMIM constructs, including Issue Importance, Outcome Assessments, and Information Discrepancy. Issue Importance and Outcome Assessment emerged as significant in this adjusted model, with patients who agreed that it is important to know what others think about my transplant options (Issue Importance) and that there were more benefits than problems to discussing transplantation (positive Outcome Assessments) being almost three times more likely to have had discussions (OR=2.650, 95% CI=1.077-6.520; OR=2.797, 95% CI=1.077-7.261, respectively).

 In block 3, Perceived Ability variables were included, which increased the model fit by two percent (from 0.201 to 0.223), such that 22 % of the variance of having transplant

discussions was explained when accounting for sociodemographics, TMIM constructs and perceived ability. Patients who agreed that there were more benefits than problems when discussing kidney transplantations (Outcome Expectancy) continued to be significantly more likely to hold discussions (OR=3.021, 95% CI=1.137-8.024), and, to a lesser degree, Issue Importance also remained a significant predictor (OR=2.460, 95% CI= .971-6.229).

However, the addition of Patient Empowerment constructs (block 4) reduced the significance of the Issue Importance construct to a non-significant level (p=.123) and also reduced the level of significance for the predictive function of positive Outcome Assessment, although this remained marginally significant (p=.058). In controlling for Patient Empowerment, age began to emerge as a potentially significant variable (p=0.069). With each additional year of age, individuals were 1.03 times more likely to have had a discussion. Further, the Patient Empowerment construct related to hope (I agree transplantation can help me) emerged as marginally significant (p=.085), with patients who reported agreement being approximately 3.2 times more likely to have had discussions with others (OR=3.216, 95% CI=0.850-12.175).

The belief that transplantation was helpful continued to be marginally significant (p=0.084) in block 5, with the addition of patient Self Efficacy to the model. Those who agreed that the benefits outweigh the problems to discussing transplant were now over 2.5 times more likely to discuss transplant (OR=2.594, 95% CI=0.944-7.134), however significance was reduced from the initial iteration of the model (p=.075). With the addition of the Self Efficacy construct, the model fit dropped slightly by .2 percent (from .257 to .255).

In the fully adjusted model, with the addition of transplant knowledge score, the Patient Empowerment hope construct (Agree that transplantation can help me) was no longer significant.

The TMIM construct of positive Outcome Assessments (there are more benefits to discussing transplant than problems) continued to be marginally significant (p=0.095) with those who agreed that transplant discussions were beneficial being 2.4 times more likely to have had conversations (OR=2.420, 95% CI=0.859-6.822). In the fully adjusted model, age was also marginally associated (p=0.077) with the odds of having a conversation with others about transplantation (OR-1.031, 95% CI=0.997-1.066). The addition of the knowledge construct also increased the model fit, the final adjusted model accounts for approximately 26.3 percent of the variation between those who did and those who did not discuss transplantation with others.

Table 8. Binary Logistic Regression Model: Predicting the odds of having a Transplant Conversation by Sociodemographics, TMIM Constructs, Perceived Ability, Patient Empowerment, Self Efficacy and Transplant Knowledge Variables significant in bivariate analysis

Key Predictors	Block 1 B (CI) p-value	Block 2 B (CI) p-value	Block 3 B (CI) p-value	Block 4 B (CI) p-value	Block 5 B (CI) p-value	Block 6 B (CI) p-value
Age	1.018 (.989-1.049) .228	1.025 (.993-1.058) .122	1.027 (.995-1.061) .101	1.031 (.998-1.066) .069*	1.031 (.997-1.065) .076*	1.031 (.997-1.066) .077*
Non-Hispanic White [a]	1.788 (.797-4.010) .159	1.722 (.737-4.026) .210	1.860 (.770-4.495) .168	1.855 (.743-4.630) .185	1.940 (.748-5.030) .173	1.778 (.680-4.651) .241
Married [b]	1.753 (.791-3.884) .167	1.876 (.812-4.334) .141	1.814 (.770-4.276) .173	1.807 (.748-4.363) .188	1.818 (.752-4.395) .185	1.808 (.745-4.387) .190
Income [c]	.719 (.319-1.618) .425	.820 (.350-1.923) .648	.786 (.328-1.881) .588	.694 (.274-1.758) .441	.691 (.273-1.750) .435	.734 (.287-1.878) .519
Agree it is important to discuss transplant options. [d]		.946 (.320-2.790) .919	.897 (.290-2.767) .849	.694 (.274-1.758) .918	.832 (.245-2.824) .768	.925 (.267-3.206) .903
Agree it is important to know what others think of my transplant options. [d]		2.650 (1.077-6.520) .034**	2.460 (.971-6.229) .058*	2.126 (.816-5.542) .123	2.059 (.782-5.419) .144	2.169 (.816-5.766) .121
Agree there are more benefits to discussing transplant than problems. [d]		2.797 (1.077-7.261) .035**	3.021 (1.137-8.024) .027**	2.595 (.944-7.134) .065*	2.548 (.909-7.143) .075*	2.420 (.859-6.822) .095*
Agree I wish I knew more about others' opinions on my transplant options [d]		.965 (.431-2.163) .932	.920 (.400-2.112) .843	.992 (.423-2.330) .986	1.028 (.434-2.434) .950	1.035 (.435-2.466) .938

Agree I know enough about live donor kidney transplantation to hold a conversation about it. [d]			2.060 (.625-6.791) .235	1.626 (.466-5.670) .446	1.643 (.464-5.810) .441	1.405 (.394-5.018) .600
Agree I know enough about deceased donor kidney transplantation to hold a conversation about it. [d]			1.281 (.417-3.931) .665	1.312 (.416-4.137) .643	1.206 (.360-4.040) .762	1.260 (.380-4.175) .705
Agree I know what to expect with my health. [d]				1.324 (.580-3.023) .506	1.306 (.569-2.995) .529	1.294 (.561-2.983) .545
Agree I feel transplantation can help me. [d]				3.216 (.850-12.175) .085*	3.261 (.855-12.441) .084*	3.047 (.792-11.715) .105
Agree I can control the course of my own healthcare. [d]				1.623 (.739-3.564) .228	1.539 (.688-3.445) .294	1.511 (.670-3.405) .320
Confidence Sum Score					1.001 (.999-1.002) .564	1.000 (.998-1.002) .765
Knowledge Sum Score						1.153 (.924-1.439) .209
Adjusted R^2	0.088	.201	.223	.257	.255	.263

Notes: Source – COACH study (2012-2015). Includes variables significant in bivariate analysis at the $\alpha = .1$ level. (N=184). B=standardized regression coefficient with 95% Confidence Interval in parentheses; *p<.1; **p<.05; (two-tailed tests). [a] Non-white omitted category; [b] not married omitted category; [c] $39,999 or less omitted category; [d] Disagree omitted category

Discussion

It is important to note that this study is exploratory in nature. However, several hypotheses were specifically tested in this analyses based on the current literature regarding social communication theories, and kidney transplantation. I posited that ESRD patients would express a discrepancy in the amount of information they have regarding others' perceptions of transplantation, as an awareness of this discrepancy is a first step towards information seeking behaviors. Slightly more than half of patients in this study expressed an information discrepancy at 58.5%. While this finding is indicative of information discrepancy, it is not a definitive result. However, the fact that those who reported an information discrepancy were more likely to report having conversations (76.6% as compared to 64.5%; p=.096) warrants further consideration and may support the first stage of the TMIM.

I also hypothesized that a heightened negative emotional response resulting from the uncertainty discrepancy would be negatively related to positive outcome assessments and higher efficacy assessments. Results from this analysis did not support this hypothesis, and anxiety surrounding the information discrepancy was not significantly correlated with either outcome assessments or efficacy assessments. However, TMIM acknowledges that other emotional responses may be activated when an individual experiences an information discrepancy, and it is possible that anxiety is simply not the best construct to assess when considering kidney transplant patients (Morse et al., 2009).

In accordance with the next phase of the TMIM model, I theorized that positive outcome expectancies would be positively related to efficacy assessments. In bivariate analysis, this correlation was perhaps the strongest (p=.000), indicating that patients with more positive assessments of the potential outcomes of transplant related conversations felt greater efficacy in

their ability to engage in specific communication strategies related to transplant conversations. Outcome assessments may also be a modifiable variable useful in promoting transplant related communication, through providing examples of successful conversations to patients.

Also based on the TMIM, I posited that higher efficacy assessments would be positively related to the decision to seek information. In bivariate analysis, higher efficacy was positively correlated with discussions about transplantation; however when entered in to the regression model this variable was not significant and, to a small extent, reduced the percentage of the variability in this population that the model explained (inclusion of this variable in block 5 reduced the adjusted R^2 from .257 to .255). While significant in bivariate analysis, when considered with other variables self-efficacy does not appear to be a predictor of information seeking behaviors. This relationship should be further explored to assess for potential multi-collinearity or suppression affects; such analyses were beyond the scope of this paper.

My final hypothesis related to the usefulness of the Patient Empowerment model and potential for integration in to the Theory of Motivated Information Management as an additional modifiable factor for this population. I hypothesized that there would be a negative association between Patient Empowerment and anxiety related to the information discrepancy, with the understanding that such an association could be used to mitigate the impact of anxiety on outcome and efficacy assessments. However, no significant association between anxiety and outcome or efficacy assessments resulted from this research. Nonetheless, in bivariate analysis, the Patient Empowerment measures for control (Agree I have control over my kidney disease) and hope (I hope my condition will approve) were both associated with lower anxiety related to the issue at the $\alpha = .1$ level of significance.

While the fully adjusted model accounted for only a small portion of the variation in discussion of transplantation (.263), Outcome Assessment remained moderately significant (p=.095). It is important to note that complete iterations of the TMIM include additional Outcome constructs, and include not just Outcome Expectancies– the anticipated result of a specific behavior or action, but also *Outcome Importance (OI)*-the relative usefulness of the expected outcomes and; *Outcome probability (OP)*-the "perceived likelihood that the outcome expectancies will actually occur" (W. A. Afifi & Weiner, 2004; 176). These additional constructs may have strengthened this model. While this analysis is only exploratory, it does offer some support for the predictive value of TMIM in the context of transplant related conversations, and warrants further exploration and a more tailored approach to data collection and analysis in order to fully assess the usefulness of this model.

Limitations

There are some limitations to this study that should be considered. First, the sample population was recruited from two mid-Atlantic transplant centers, and thus lacks generalizability to other populations. The data used for these analyses were retrofitted to the theories under consideration; while the COACH study was informed by the theories of TMIM and Patient Empowerment, the goal of COACH was to assess the efficacy of an intervention and not the predictive power of this communication model. Thus, some variables were not constructed in an ideal manner for this research and certain TMIM domains were missing from the model. This analyses also did not control for some other potential confounding variables, such as beliefs about the acceptability of transplantation which has been implicated as an important factor in communication about transplantation (Rodrigue et al., 2008). Finally, due to the nature of the data collection process, some participants would have had more time for

conversations than others; it is possible that participants may have intended to have a conversation or even planned to have one, and this analyses did not capture and account for that. Future research might consider including a variable for "Intention to discuss transplantation" as a measure of future plans for transplant conversations.

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